The Decision to Know

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Kirsten M. Kringle

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Advised by Naomi Scheman

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To Amy Hilden who saw my potential,

and Naomi Scheman who helped me see it too.

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Chapter 1: Framework and Guiding Questions

There is a sense in which the solution to the question 'Should we pursue knowledge of *x*?' might strike us as an easy one. Knowledge has been, and continues to be, understood as unquestionably valuable, not just within the confines of academic philosophy, but also in the wider setting of our everyday lives. This drive for and love of knowledge, when taken to extremes, has even been given a name: epistemophilia (Townley 37). In the work that follows, I will challenge the inclination to uncritically suppose that we should pursue knowledge of *x*—at least not without careful consideration of what 'knowledge of x' amounts to in the context of our deeply relevant, though often ignored, subjective life-circumstances.

A few key questions stand out as those for which I would like to provide an answer through the course of this inquiry. The most central of all is undoubtedly this: is knowledge always better than ignorance? More specifically, are there special cases where it would be epistemically virtuous for us to avoid the seeking of knowledge at all costs, and prefer not-knowing, or knowing-that-we-don't-know? What are these special cases? What are potential mitigating circumstances?

I will argue that, in some cases, pursuing knowledge is not always advisable. I will be careful to distinguish between cases where the knowledge itself is harmful, and cases where the pursuit of knowledge is harmful. I will maintain that there are instances of each, and both are relevant when we turn our focus to instances of epistemic harm. For it does not seem surprising that knowledge can be harmful to us emotionally. The knowledge that I am a carrier of a gene predisposing me to breast cancer, or that my partner has been unfaithful, are virtually uncontested examples of

cases where knowledge can be emotionally harmful. More surprising is my claim that in some cases knowledge, and the pursuit of that knowledge, can be harmful to us as knowers. Although my thesis resists our ordinary intuitions, I will show that there is at least room for such a position within the framework of virtue epistemology and there are even a few voices willing to join in.

In saying that pursuing knowledge can be harmful to us as knowers, it seems like I am saying that pursuing knowledge is getting in the way of having knowledge. This is because harm to us as knowers just sounds like anything that prevents us from achieving knowledge. This is the wrong way of thinking about my project, and a way of thinking that I need to be really careful to avoid. There are certain types of knowledge, such as biomedical/scientific knowledge, that can get in the way of other ways of knowing, such as knowing what it is like, knowing how to get things done, and social/personal knowing. I argue that preference for information seeking of the biomedical/scientific type can be harmful to us as knowers because it shuts off avenues for other epistemic goods. Knowing what it is like, I believe is a distinct end product from simply gleaning information of the biomedical/scientific type we have come to prefer as a society.

A real tension arises when, on the one hand, I want to focus my inquiry on harms that are specifically of an epistemic variety, and, on the other hand, I want to say that knowledge and the drive for knowledge aren't necessarily good. If epistemic harms cash out in terms of harm to us as knowers (which I think they do), it is hard to see how these claims can be made to be consistent. Isn't harm to us as knowers harm

that just interrupts our achievement of knowledge? At first blush, it certainly seems so. I do, however, see at least one potential approach to resolving this tension.

Perhaps what we mean by harm to us as knowers is not simply the interruption of knowledge acquisition. When we talk about ourselves as knowers, it is my contention that we mean something more robust than merely vessels of knowledge. Or, if that is what we mean, then it must be the case that we mean something more robust by 'knowledge' than simply warranted propositional beliefs. The problem arises, it seems, from thinking about knowledge as something separate or separable from all of the other things that we do—from thinking about ourselves as knowers as somehow ourselves abstracted from ourselves as mothers, lovers, or baseball players.

The problems raised in traditional epistemology are those best represented by this kind of purification of the subject and the object of knowledge. But these aren't the real subjects or objects of knowledge. Knowledge is often not of the straightforward propositional variety preferred by epistemologists, nor are knowers somehow separable from the other roles they take up. Take the problem of testimony, for example. As it arises in the literature, the problem is not phrased as "as the kind of person we are, how much authority can we ascribe to a speaker, as the kind of person they are, about some claim, as the kind of claim that it is?" Yet, this is how it presents in actuality: as a patient, how much authority should we ascribe to our doctor about the claim that we should take a certain medication? As a citizen, how much authority should we ascribe to the Chairman of the Federal Reserve about the claim that the economy may enter a double-dip recession?

Instead, we are asked to consider the problem of testimony abstractly. That is,

regardless of the kind of person we are, how much authority should we ascribe to some speaker, regardless of the kind of person they are, about some claim, regardless of the kind of claim that it is? How often does the problem of testimony present itself regardless of who we are, or who the speaker is, or of the nature of the claim? It is my contention that it doesn't ever present this way. Or, if it does, it is not at all representative of the problem of testimony as we most often face it. It is not just that what is interesting is missed when we abstract away features of the world for some artificially purified case of knowledge; it is that what is real is missed. For this very reason, the fiction of a detached observer—some fragment of ourselves able to step outside of the situation, take in information, assess, and reengage, needs to be avoided.

So what features do we need to include about knowers to make our theorizing about them productive and applicable? We have two complimentary options for solving this puzzle. First, if we retain a picture of us as knowers similar to mere vessels, then what picture of knowledge will suit? How will the inclusion of these features of this broader notion of knowledge avoid the tension I in my project that I identified above? That is, if we do not have a detached conception of ourselves as knowers and an abstract conception of knowledge, can we avoid the worry about pitting knowledge against our needs and interests as knowers?

To begin, let us address the additional features of knowers and knowledge that we might need then investigate why including them situates us to avoid the tension that has arisen. Approaches to epistemology that suggest some possible features of

knowers and knowledge relevant to resolving this tension include feminist epistemology and virtue epistemology—feminist epistemology because it unequivocally argues that features of the knower (in particular, the gender of the knower) are relevant to identifying and characterizing cases of knowledge.

In her essay, "Taking Subjectivity into Account," Lorraine Code argues that relevant factors concerning a subject's situatedness, such as race, class, or gender, ought to be considered in any investigation of what the subject can or cannot rightly be said to know. She writes, "…conditions that hold for any knower, regardless of her or his identity, interests, and circumstances, in other words of her or his subjectivity—could conceivably be discovered only for a narrow range of artificially isolated and purified empirical knowledge claims, which might be paradigmatic by fiat, but are unlikely so 'in fact'" (Code 191). She argues for what she calls an "epistemology of everyday lives" and urges that we turn away from artificially sterilized models of knowledge that steer clear of what she takes to be the highly relevant circumstances of located knowers (Code 192).

Code begins her argument with an assault on traditional "*s* knows that *p*" epistemologies for their (often implicit) assumption that '*s*' and '*p*' are merely place holders which can be replaced by any *s* or any *p*, and maintain efficacy. When you begin to scrutinize the kinds of things you substitute for *s* and *p*, however, such a schema loses its capacity to represent many natural knowledge claims. According to her interpretation of such approaches to representing knowledge claims, it follows that: "If one cannot transcend subjectivity and particularities of its 'locations,' then there is no knowledge worth analyzing" (192). Only a narrow subset of human

knowledge claims, according to Code, can be isolated and analyzed by an epistemology which does not attend to the subjectivity of the knower.

For Code, and for us, the *location* of the knower—his or her social identity, interests or desires, and circumstances of her situation—make it the case (or not) that some knowledge is desirable, undesirable, or even possible. As knowers we are not different from ourselves as patients or poets. What we can be said to know, what we set out to know, is limited, shaped, and driven by our location. Knowing is not something that we do apart from all of the other things that we do. Knowing is embedded in, constitutive of and constituted by our locations.

The implication of this wider view of ourselves as knowers for the resolution of the tension arising from supposing that knowledge can be harmful to us as knowers means that harm caused to us by the pursuit or acquisition of knowledge that influences our location too influences us as knowers. Knowledge or knowledge seeking that changes our relationship with our spouse, children, or coworkers changes us as knowers. It circumscribes what we can know, how we can know, if we should know, whether we want to know, and so on. It could be objected here that a consequence of this claim is that any harm is an epistemic harm. Suppose you are cut from the basketball team. This amounts to an epistemic harm in that you no longer satisfy the role of basketball player and any and all knowledge available to you through that role is no longer accessible to you. In a way, this seems right, but it is not the kind of case that I am interested in. I am interested in cases where our *epistemic* behavior, or the epistemic behavior of others, impacts us as knowers, and potentially doing so through impacting us as the other kinds of things that we are.

I want to be even more careful here, however, and point out further that I am also not focusing on epistemic behavior that is necessarily malicious or otherwise morally objectionable. Spying on someone, torture, or reading another's personal diary are examples of efforts at obtaining knowledge that are *malum in se*, and can clearly cause harm (emotional, physical, epistemic) to both the subjects and the objects of knowledge. I am, instead, interested in problems that attach to coming to know, but not just because we are going about obtaining that knowledge in a bad way. Asking a mutual friend about the circumstances of a potential date's messy divorce shuts down ways the date may come to tell you something about the situation. It is not morally wrong to ask your friend ahead of time, but it does potentially limit what you stand to gain from the individual themselves, and further, it can undermine your prospective date's role as a legitimate source of knowledge about themself.

To sum up, then, the implication of the wider view of ourselves as knowers for the resolution of the tension arising from supposing that knowledge can be harmful to us as knowers means that harm caused to us by the pursuit or acquisition of knowledge that influences our location also influences us as knowers. We have further limited cases of interest to those of harm caused by epistemic activity, and specifically epistemic activity of a non-morally objectionable type. While the above considerations are promising for resolving the tension at issue, we are still left with an additional avenue of pursuit. Rethinking what we mean by knowledge is an additional (but not incompatible) approach for resolving the tension between knowledge and epistemic harm. Again, what we want to avoid is a depiction of knowledge that is somehow separate or separable from all of the other things that we do. Similarly, we

want to avoid a narrowing of the epistemic, or the conflation of knowledge with epistemic good. Virtue epistemology is certainly poised to avoid this confusion.

Virtue epistemologists themselves, however, seem to operate with something of a pretheoretic assumption about the value of knowledge. Inquiry concerning the value of knowledge in virtue epistemology and elsewhere centers around attempts at singling out the peculiar value of knowledge over and above mere true belief (a fact which suggests that there *is* some presupposed value for which they are making a case). How this value can be said to be attributed to knowledge largely focuses on the route taken to achieving it. For virtue epistemologists, the answer lies in determining whether it was the subject's intellectual virtues that led him or her to said knowledge. A belief gained by accident or luck is regarded as less valuable than one gained through, for example, scrutiny, open-mindedness, or intellectual courage. In fact, it is a key contention of many virtue epistemologists that appealing to such intellectual virtues is the *only way* to achieve a satisfactory answer to the question of the peculiar value of knowledge. In this way virtue epistemologists hope to account for the value of knowledge over mere true belief.

However, virtue epistemologists typically rely on the presumed value of knowledge in conceiving of epistemic virtues as such. Virtues, whether epistemic or moral, require a motivational component. What, according to many virtue epistemologists, makes epistemic virtues epistemic is that they are guided by a motivation for knowledge. What makes them virtues is that this motivation for knowledge is (presumably) a good one. What I want to suggest, and what would allow us to retain virtue epistemology as an approach to solving some of the problems

I have posed, is that a wider notion of what we mean by 'knowledge' can help us resolve the tension between knowledge and the avoidance of epistemic harm. Perhaps what virtue epistemologists take as virtuously motivating epistemic virtues is not knowledge simply understood. Perhaps, instead it is some wider notion of epistemic good. That is, 'knowledge' may just be shorthand for some set of ends that intellectual virtues are properly aimed at. I find some support for this suspicion in Roberts and Wood's Intellectual Virtue. The list of epistemic goods derivable from their work is not exhausted by knowledge. Instead, they include alongside knowledge understanding, appreciation, and acquaintance. In a contention that ought to feel familiar at this point, the authors write, "the focus on belief in these debates [the traditional debates of epistemology, e.g. externalism/internalism] seems to sideline some of the epistemic goods that must be kept in mind if one is to see "knowledge" fully in the context of the fullest human life […] So the epistemology that focuses exclusively on knowledge and makes knowledge some kind of belief or other had tended to neglect some of the most interesting and important aspects and kinds of knowledge (35)."

How does reconfiguring what we mean by 'knowledge' to include some of these other epistemic goods help us resolve the tension between knowledge and the avoidance of epistemic harm—that is, harm to us as knowers? Well, harm to us as knowers would, on this interpretation, include harm to us as, say, understanders or appreciaters. It is easy to see how the pursuit of knowledge (here: facts, information: knowledge that p) could undermine us as understanders or appreciaters of an object. Take a trip to your local museum as an example. Upon entering, you might be

offered a headset capable of guiding you through an audio tour of the exhibit halls. While utilizing the headset for an audio tour shouldn't be understood as wrong, the experience you will have at the museum is qualitatively different from the one you would have without using the headset. You may learn a lot more facts about the individual pieces of art, that is, become a great deal more knowledgeable about them, but the constant influx of these facts may actually impede a kind of appreciation of the art that is available to you through quiet, personal reflection, or even casual conversation with other museum-goers.

So your trip to the museum can contribute to you as a knower in multiple ways. It may be a highly informative experience, with you leaving with a stockpile of new information about art, or it may be an experience of some greater appreciation for art, one not achieved through an accumulation of facts, but instead through intimate personal reflection on a piece of art. You should be reminded here of the previous example regarding the asking of a friend about the details of a past divorce of a potential date. In both of these cases, the way we have pursued information is not in any way wrong, but it can still be understood as limiting us as knowers—in that we are potentially limiting an understanding of the divorce available through the prospective date alone, or an appreciation of art available through our own personal encounter with it, one not mediated by a stream of propositional facts about the artist or the artwork itself. Certain ways of coming to know can get in the way of a proper understanding.

To bring us back full-circle then, Roberts and Wood write "the functioning of 'intellect' is shot through with 'will.' The life of the intellect is just as much a matter

of loves, concerns, desires, emotions and the like as other parts of our lives" (40). A more robust picture of ourselves as knowers, or of what we mean by knowledge helps us understand how knowledge, when conceived of simply (i.e. facts, information), and the pursuit of that knowledge may be harmful to us as knowers. It may impact our ability to achieve other epistemic ends (e.g. understanding, appreciation) or it may alter our location. The tension, then, between knowledge and the avoidance of harm to us as knowers is only apparent.

The central claim of this project, then, is that there are instances where the pursuit of knowledge inhibits our epistemic well-being. In these instances we are better off epistemically to resist the urge to pursue (certain sorts of) knowledge, recognize our ignorance and, in so doing, enhance our epistemic well-being.

I believe that a schema borrowed from nursing epistemology will be helpful in guiding us through the remainder of this work: Liaschenko and Fisher develop a highly useful framework in nursing epistemology for the types of knowledge used by nurses on the job. It includes three primary types of knowledge: biomedical/scientific; patient knowledge; and person knowledge. These types of knowledge are connected by social knowledge.

Biomedical/scientific knowledge is the type of knowledge that nurses gain both on the job and in their schooling. It has to do with anatomy and physiology, different technologies used in patient care, such as EKG's and ultrasound, and knowledge of pharmaceuticals.

Patient knowledge is understood by Liaschenko and Fisher as biomedical/scientific knowledge now applied to the case at hand. So patient

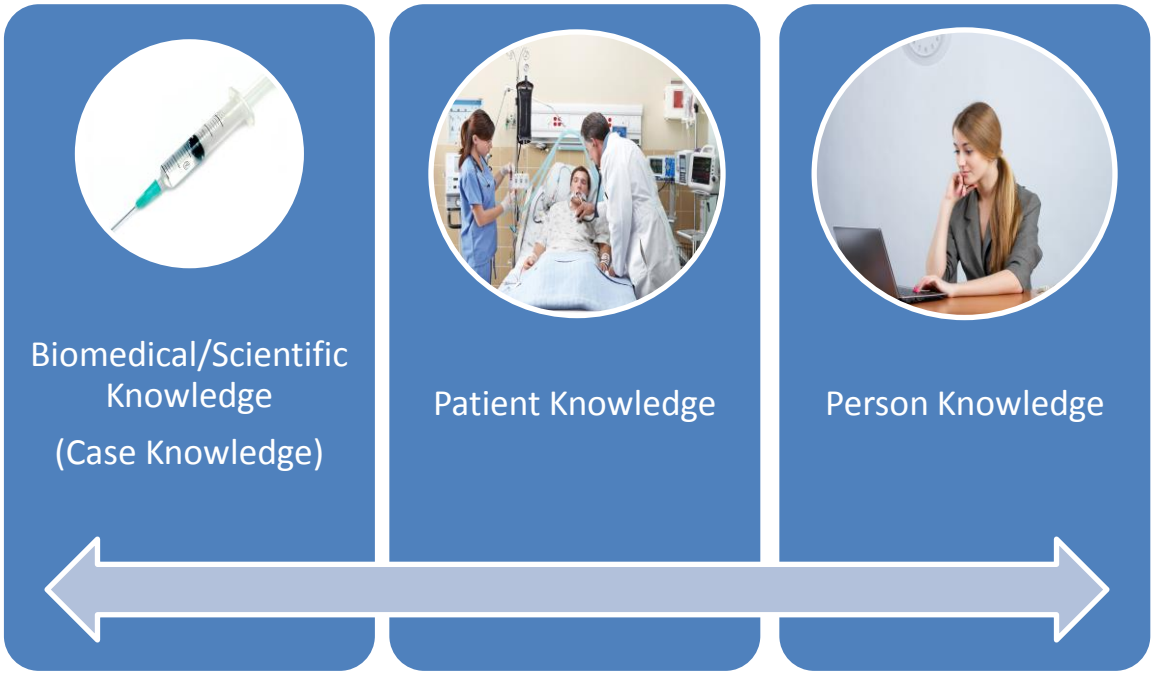
knowledge has to do with monitoring how the patient is responding to therapeutic practices employed in their case.

Person knowledge has to do with the patient in the context of their everyday life. It requires testimony from the patient and perhaps family or friends regarding what kind of work they do, what their home life is like, what relationships and help they have, etc.. Liaschenko and Fisher have reservations about the amount of person knowledge it is appropriate for nurses to have in a given context. It is my contention that person knowledge is undervalued.

Liaschenko and Fisher argue that *social knowledge* connects these three types of knowledge. For example, social knowledge connecting biomedical/scientific knowledge to patient knowledge might be the knowledge a nurse has of a particular surgeon. They may know things about the surgeon such as what types of pain medication they tend to order for their patients, how practiced they are and what techniques they use for a given surgical procedure, etc. The social knowledge connecting patient knowledge to person knowledge would include things like what the family members say or know about the patient's wishes, information gleaned from other nurses about the patient at shift change, etc.

Here is a depiction of her framework of nursing knowledge as they see it:

Figure 1.1 Nursing Knowledge



I want to argue two things about this framework: First, I believe that it has wider applicability than to just nursing knowledge. I believe that it can help us understand much more than the types of knowledge nurses have. I believe that it applies to physicians, patients, and the general public. While the issues I raise are especially relevant in heath care contexts, I will demonstrate in my conclusion that they have wider applicability.

Second, I believe that something goes wrong when one of these types of knowledge is privileged over others. That is, when we have a preference for (as a society, as healthcare consumers and workers) biomedical knowledge, the other two types of knowledge, most importantly, person knowledge gets pushed aside.

Prospectus

Before continuing then, it is prudent to give a brief overview of

the project that follows:

The knowledge-seeking behavior that guides scientific, academic, and everyday inquiry is ordinarily thought to be harmless, even heralded. If given the option to know *x* or not to know *x*, I am likely to choose to gain that lacking knowledge of *x*. It is this inclination that has driven my academic career in philosophy and the sciences. I am curious. I seek out knowledge where there is wonder. This tendency in myself was abruptly challenged by a personal experience I had with pursuing knowledge of my unborn child during pregnancy. The impetus of my project is captured in the investigation encompassed by the second chapter of this project. I began asking relatively harmless questions of my own pregnancy: Was she healthy? Was she growing well? Was she safe? Was she ready to enter the world? The desire to replace worry, even wonder, with knowledge set off a seemingly irreversible chain of events resulting in an undue escalation of intervention in pregnancy; this escalation led to considerable epistemic harms suffered by me, the mother, and completely unnecessary physical harms suffered by my child.

Pregnancy is normally accompanied by a good deal of questioning. Is the baby healthy? Is it a boy or a girl? When is she due? But these questions, and the well-established routes taken to answering them in perinatal medicine, are highly capable of running amok. One such method—the use of ultrasound in a normal pregnancy—is precisely what set off a physically and epistemically harmful escalation of medical intervention during my pregnancy. The suspicious but merely probabilistic results of an ordinary 20-week ultrasound led to two amniocenteses, weekly ultrasound imaging, emergency cesarean section surgery, and early delivery.

Physical harm aside, in this chapter I will explore the serious epistemic harms caused by the escalation of intervention in pregnancy and the relentless pursuit of medical intervention. I will rely on the help of Barbara Katz-Rothman and Miranda Fricker to show that the pursuit of medical intervention in my pregnancy amounted to epistemic imperialism and resulted in hermeneutical injustice. This example illustrates for us a case where the questions being asked and the attempts at answers given are set out by someone other than the person who ought to be in charge—the mother. This infraction makes her a victim of hermeneutical injustice, a flavor of epistemic injustice characterized by infringement upon the sufferer's ability to make meaning for him or herself (Fricker 147).

What I believe is uniquely interesting about this case of hermeneutical injustice, and what makes is central to our conversation, is that I am not arguing that the mother (mothers, me) has some kind of special access to knowledge unavailable to her providers. Instead, what *is* being argued is that the preference for having the kind of knowledge available through medical diagnostics may be unfounded, and the quest for this kind of information disrupts the course and experience of pregnancy. I believe that this issue translates more generally, and that the quest for certain kinds of knowledge, when inattentive to the peculiarities of the knower and the known, is not always advisable.

In this chapter I will demonstrate that it is critical to attend to motivation, privacy, probabilistic knowledge, distribution of epistemic agency. I will suggest some strategies for moving toward solutions, including an anecdote from Wittgenstein, and particularly, the work of Lorraine Code on the subjectivity of the

knower and the known. I take this to be an exceptionally personal example of a circumstance where knowledge-of-*x* may not be preferred to ignorance. This example evidences one of the few instances where the knowledge itself was harmful.

My third chapter investigates the role of epistemic imperialism (unduly privileging knowledge of a certain sort, and methods of achieving knowledge of a certain sort, over other available knowledge/methods) and power imbalances between physicians, patients, and nurses in how nursing knowledge is received, represented, and understood by not simply the players at stake (e.g. the physician, patient, and nurses) but also the general public. I argue that what nurses know, and the work that they perform is often rendered *invisible* to patients, physicians, nurses, and the general public by the function of these power structures and epistemic imperialism.

Nurses operate with three types of special knowledge: case (biomedical/scientific), patient (applied case knowledge), and person (biographical knowledge of patient) and because they operate with patient and person knowledge rather than just case knowledge (biomedical/scientific knowledge), they are better able to care for patients in the face of ignorance about the biomedical/scientific knowledge than physicians are. Because nursing is a boundary discipline, in that it operates both in and between two very different realms of knowledge (the scientific/biomedical realm and the subjective/personal realm), much of what nurses are up to in their day-to-day tasks is unseen or unacknowledged by patient, physician, and public and is not even recognized by nurses themselves as constituting *work* (Stein-Parbury and Laischenko, 2007; Laischenko and Fisher, 1999).

In chapter three I will discuss, through personal narrative this imbalance in power between nurses and physicians. I will demonstrate that there is not just a hierarchical power structure at play, but also an imbalance of epistemic power and what is taken to be valuable knowledge. I will argue that this case brings to light issues of testimonial injustice, privileging certain kinds of knowledge over others, the relationship between love, care, trust, and knowledge. Finally, I will look at solutions including a shared knowledge base for doctors and nurses, overcoming epistemic imperialism, as well as some inferences from Miranda Fricker on overcoming testimonial injustice.

In my fourth chapter, I will explore the understanding of minority groups—in this case, individuals who identify as disabled. I will demonstrate that hermeneutical injustice, as conceived by Miranda Fricker and José Medina, is at play as well as intentional ignorance, and ignorance as a tendency, in line with the work of Charles Mills. I will suggest some solutions including epistemic humility, recognized ignorance, and, most robustly, Maria Lugones' notion of "World traveling." In this section, I will explore the notion of Hermeneutical Injustice, as coined by Miranda Fricker, yet operate with a somewhat revised conception of what is meant by hermeneutical injustice—one which has been deeply informed by José Medina's work with the term. In this conception, I agree that there is indeed an epistemic injustice occurring—the inability of an individual or group to make sense of his, her, or their experience—but attend to the concern of *to whom* they are attempting to make sense of these experiences. In line with Medina, I argue that it is possible for an individuals and groups to make sense of and regardless of hegemonic uptake. Thus,

hermeneutical injustice occurs when there is no corresponding uptake by the dominant discourse. I argue that hermeneutically marginalized groups are indeed bestowed with hermeneutical resources and that, furthermore, in line with the contentions of Medina, they are even possibly better positioned to possess epistemic virtues less accessible to those who are not epistemically and generally oppressed. I argue that, since we are all contributors to the hermeneutical resources of the dominant discourse, we are all obliged to make room for divergent views.

Finally, in fleshing out what these obligations look like, what they amount to, I will turn to the work of Mariá Lugones and argue that it is only through sustained, often uncomfortable, interpersonal contact with the epistemic other that we can overcome hermeneutical injustice. Moreover, I will demonstrate that *knowing what it is like* is the distinct end product of this contact, which Lugones terms "world traveling" and that, in order to fully appreciate and know what it is like, one has to struggle with and possibly abandon some, perhaps many, of our self-perceived identity traits. Knowing what it is like via world traveling necessitates dramatically altering our own identity.

In this chapter I want to explore not simply this case of testimonial injustice, but also how ignorance plays a role in my project. I will explore the discipline of epistemology of ignorance, which maintains that ignorance is more than simply a lack of knowledge. It is something worth theorizing about. A forerunner in the epistemology of ignorance is Nancy Tuana. She writes in defense of her pursuit that

> It is important that our epistemologies not limit attention simply to what is known or what is believed to be known. If we are to fully understand the complex practices of knowledge production and the variety of features that account for why something is known, we must also understand the practices that account for not knowing, that is, for out lack of knowledge about a phenomena or, in some cases, an account of the

> practices that results in a group unlearning what was once a realm of knowledge. In other words, those who would strive to understand how we know must also develop epistemologies of ignorance.¶ Ignorance, far from being a simple lack of knowledge that good science aims to banish, is better understood as a practice with supporting social causes as complex as those involved in knowledge practices. (194-195)

By drawing on the work of Nancy Potter, Mariá Lugones, Nancy Tuana, and others, I will explore the important role ignorance plays in trust and knowledge across lines of power and privilege. Of course, unacknowledged ignorance has played an important role in constructing inequalities, especially epistemic inequalities. However, recognized ignorance and acknowledgement also has an important role to play in healing them. Recognizing that there are things you don't know, even things you can't know, about another is critical to rightly understanding them as full-fledged epistemic agents.

I will then conclude my work with a summary of the problems raised in chapters two through four. I will offer a robust potential solution incorporating insights from suggested solutions raised in chapters two through four. I will highlight the epistemic harms we have encountered including: (1) epistemic unsustainability—pursuing knowledge in reckless or disrespectful ways which prevent you or any who comes after you from ever gaining knowledge from that source again in the future; (2) epistemic imperialism—unduly privileging knowledge of a certain sort, and methods of achieving knowledge of a certain sort, over other available knowledge/methods; (3) losing knowledge by raising our standards of proof for what we count as knowledge (I will argue that we can actually lose knowledge we once had); (4) testimonial injustice—where we do not count information gleaned from someone's testimony as knowledge without corroboration—corroboration achieved

by bending over backward to verify (or even undermine) that person's claims; (5) and finally, hermeneutical injustice—when a knower's ability to make meaning for herself is compromised.

I want to take a moment to make clear these five epistemic harms, as they play a central role in my work:

> (1) Particular methods of pursuing knowledge are epistemically unsustainable. What I mean by this is that pursuing knowledge in a reckless or disrespectful way can close off that avenue for knowledge to those who may come after you, or even to yourself at a later time. This is in many ways similar to what is captured by the old adage of "burning bridges," but more specific in that the bridges we are interested in here are those that lead to the knowledge we are interested in. Collecting information in an epistemically unsustainable way, then, is epistemically harmful in that is limits our capacity for gaining additional knowledge in the future.
>
> (2) Certain information seeking practices are epistemically imperialistic. That is, they unduly privilege knowledge of a certain sort, and methods for achieving knowledge of a certain sort, over other available knowledge/methods. What is epistemically harmful in cases of epistemic imperialism is similar to what occurs in cases of epistemic unsustainability. Here, rather than burning bridges once we have crossed over them, we are choosing one bridge out of many, and burning the rest! Rather than limiting our access to knowledge in the future, we are limiting our access to knowledge we could have right now.

(3) An epistemic harm closely related to (2) is that of losing knowledge we once had by raising our standards of proof. Perhaps enticed by the promise of *certain* knowledge or unsettled by the presence of doubt, we may be persuaded to alter our standards of proof for knowledge. Where we once had knowledge, say, the knowledge that our partner was faithful, by raising the standards for what we are willing to count as evidence, we stand to lose that knowledge. Knowledge based on trust can be eliminated by requiring proof of a different sort—empirical, verifiable proof. Clearly, losing knowledge we once had is a case of epistemic harm.

(4) Relentlessly pursuing knowledge can lead to an epistemic harm termed 'testimonial injustice' by Miranda Fricker (9). We do not count information gleaned from their testimony as knowledge without corroboration. When we bend over backward to verify (or perhaps undermine) claims made by an individual or a group of people, we subject them to testimonial injustice. Committing testimonial injustice is not merely epistemically harmful to the guilty party; testimonial injustice is likewise epistemically harmful to the victim.

(5) Our final flavor of epistemic harm has similarly been identified and explored by Fricker: hermeneutical injustice (147). Hermeneutical injustice occurs when a knower's ability to create knowledge, to make meaning for herself, is compromised.

After reviewing the epistemic harms and solutions in the conclusion to my project, I will suggest an account of wisdom that will help guide us through these types of

cases. I will spell out how a larger scale conception of posited solutions addresses the overarching problems while making it clear that there are implications of my findings outside questions in medicine and suggesting future directions this work could take.

Philosophical Framework and Methodology

My project will primarily be situated within the framework of feminist epistemology, but will also borrow from virtue epistemology. Briefly, then, let's tour the landscape of this discipline. Many virtue epistemologists maintain that the traditional questions in epistemology, and the traditional attempts at answers given, are too narrow to capture what ought to be epistemology's central focus. The proper focus of epistemology should, instead, be on the knower and her epistemic virtues, and on the community of that knower. It is this contention of virtue epistemology to which I am sympathetic, and why I think virtue epistemology is one proper framework for my project.

I want to turn now to a discussion of some of the arguments being made in virtue and feminist epistemology which help to pave the way for my project. While what is presented here is merely a preview of how I intend to make my case, this discussion will give you a sense of how I intend to legitimize the questions I am asking, the way I go about answering them, and the proposed answers themselves.

The first proposed avenue for my project comes from an essay entitled, "Love and Knowledge: Emotion in Feminist Philosophy," by Alison M. Jaggar. Though the thrust of her argument is somewhat ancillary to the project at hand, she, in several places, chides us for supposing that knowledge-seeking can be free from the influence of social values. She writes, "these values are implicit in the identification of the

problems that are considered worthy of investigation, in the selection of hypotheses that are considered worthy of testing, and in the solutions to the problems that are considered worthy of acceptance" (176). What is being suggested here is that, not only are our routes to acceptable answers to questions being set out for us (e.g. quantitative research, medical testing, etc.), more fundamentally and more frighteningly, so are the questions themselves! In line with this suggestion, then, it is time we carefully consider who set out the important questions to which we seek answers, and who decided how to answer them. If it turns out it wasn't us, then we ought to wonder what value the knowledge gained by pursuing these answers has for us, without, of course, presupposing it has *any*. And, in responding to this new, more fundamental question—why not look for some novelty in approach to our coming up with our answers?

In seeking out this kind of novelty, we might be reminded of the quote at the opening of this work borrowed from Lorraine Code, "…conditions that hold for any knower, regardless of her or his identity, interests, and circumstances, in other words of her or his subjectivity—could conceivably be discovered only for a narrow range of artificially isolated and purified empirical knowledge claims, which might be paradigmatic by fiat, but are unlikely so 'in fact'" (Code 191). In traditional epistemology, Code believes that only a narrow subset of human knowledge claims can be isolated and analyzed by an epistemology which does not attend to the subjectivity of the knower.

So what kind of analysis is required to capture the natural kinds of human knowledge with which Code is concerned? In her answer to this question, I believe,

we can find justification for my approach to answering the questions with which *I* am concerned. It is Code's contention that, "the ideal objectivity of the universal knower is neither possible nor desirable, a realistic commitment to achieving empirical adequacy that engages in situated analyses of the subjectivities of both the knower and (where appropriate) the known is both desirable and possible…Objectivity requires taking subjectivity into account" (206). So, for a proper inquiry to be such, it must consider the subjectivity of what is known and who is knowing it. Paying careful attention to these factors, then, can likely be seen as a candidate for an approach to answering our questions about the value of knowledge, as well as hint at the kind of answers we might expect.

In an essay entitled, "On Judging Epistemic Credibility," from Linda Martín Alcoff we hear another call to this kind of approach (in fact, one that pushes us a bit further). She writes,

> Because experience is an event involving intentionality – involving the whole of one's life – a similar event may be experienced very differently by different persons. The interpretive process itself is both individual and social: the effort to establish meaning is performed by the individual, and subject to modification upon her critical reflectiveness, but is always conditioned by the concepts, narratives, values, and meanings that are available in her social and discursive context. (256)

Code and Alcoff, then, have added to our repertoire considerations regarding the historical, political, racial, financial, etc., situatedness of the knower, the community of knowers, and the objects of knowledge. They urge us to push past artificially simplistic epistemologies which advocate the possibility and representativeness of the fabled "view from nowhere." In line with the suggestions of Code and Alcoff, I intend to use what I find to be the approach best suited to addressing issues of the situatedness of the knower: the narrative approach.

An alternative way of looking at my project is to cast it in terms of the value of ignorance rather than the disvalue of knowledge. Cynthia Townley explores this approach in her article, "Towards a Reevaluation of Ignorance." She writes,

> Some ignorance should be remedied; some ignorance is harmful. But, in other ways, some ignorance contributes positively to epistemic responsibility and a lack of knowledge is not necessarily an epistemic flaw. Unless the positive role of ignorance is recognized, the full field of epistemic responsibility is obscured. Ignorance is theoretically necessary and practically valuable for certain epistemic projects precisely because knowledge does not exhaust the domain of epistemic value: epistemic agency involves more than knowledge collection. (38)

This, then, is an example of one of the few thinkers who may be sympathetic to my cause. We need to make room for considerations over and above, or at least in addition to, that of knowledge when talking about what is epistemically valuable. Townley thinks that there ought to be room for knowledge's antithesis—ignorance—in the things we take to be epistemically valuable. I enthusiastically agree. We will argue this point head on, by investigating the epistemic risks of certain forms of knowledge seeking behavior and subsequent knowledge gained; we will argue this point contextually, through narrative explorations of cases illustrating the highly relevant situated features of the knowers and objects of knowledge, and, finally, we will even argue this point upside-down and backwards, exploring the peculiar value of ignorance, both instrumental and intrinsic, as Townley and others do, and finding a rightful place for it in conversation of what counts as epistemically valuable.

In closing, I would like to explore a central assumption made by virtue epistemology, one that provided some incentive for my project. Again, I am highly sympathetic to the contention of virtue epistemology that the traditional questions in epistemology, and the traditional attempts at answers given, are too narrow to capture what ought to be epistemology's central focus. Moreover, I agree that the proper

focus of epistemology should instead be on the knower and her epistemic virtues, and on the community of that knower. For these reasons I have identified virtue epistemology as a useful framework in which to situate my project and, as discussed above, and intend to adopt many of its methodological approaches. Virtue epistemology, however, can also be regarded as something of an impetus for this project. Although not alone in doing it, virtue epistemology makes a move similar to the kind I hope to warn against in this project.

As noted above, virtue epistemologists themselves operate with something of a pretheoretic assumption about the value of knowledge. Inquiry concerning the value of knowledge in VE and elsewhere centers around attempts at singling out the peculiar value of knowledge over and above mere true belief (a fact which suggests that there is some presupposed value for which they are making a case). How this value can be said to be attributed to knowledge largely focuses on the route taken to achieving it. For virtue epistemologists, the answer lies in determining whether it was the subject's intellectual virtues that led him or her to said knowledge.

However, it is the presumed value of knowledge which many virtue epistemologists rely on in conceiving of epistemic virtues as such. What makes epistemic virtues *epistemic* in virtue epistemology is that they are guided by a motivation for knowledge. What makes them *virtues* is that this motivation for knowledge is (presumably) a good one. Hints of circular reasoning notwithstanding, for our purposes we will have to take issue with both of these contentions in arriving at a solution for the problems posed by our questions regarding the decision to know.

The motivation for knowledge, when poised to bring about certain epistemic harms and risks, cannot be haphazardly supposed to be a good one. Questioning the value of knowledge has the potential to undermine many of the projects in virtue epistemology. It is not my intention to undermine these projects, but it is my intention to subject several of their fundamental assumptions to some overdue scrutiny. What I hope to show is that the motivation required for a second-order epistemic virtue like wisdom is one that is much wider than the motivation for knowledge—one that can take into consideration potential epistemic harms for the knower and the known.

One thing that unites the cases explored in Chapters 2-4 is the way in which the relationships involved are threatened by epistemophilia. Whether it is a woman and her child, her lover, her boss, or herself, proper concern and care for these relationships requires a willingness to accept some level of ignorance. Harm to a relationship is not, by itself, epistemically harmful. However, knowing is not just something that we do, knowing is something we do tangled up with all of the other things we do and the other people that we do them with. Attention to this fact reveals the many ways in which knowledge and the pursuit of knowledge can be *epistemically* harmful to both the knower and the known. Committing or being a victim of testimonial or hermeneutical injustice, unduly privileging certain knowledge and practices of achieving it over others, violating the epistemic agency of another, and not recognizing and appreciating ignorance where it is appropriate all constitute epistemic harms, and our knowledge seeking practices need to be aimed at avoiding them where possible. It is my contention that doing so constitutes an epistemic virtue and, in the conclusion of this work, that is what I hope to establish.

Chapter Two: Knowledge Acquisition and the Escalation of Intervention in Pregnancy

Much has been done in recent years both to highlight and combat the use of intervention procedures during normal, low-risk labors, including an upsurge in the promotion and utilization of natural or alternative pain management techniques, as well as the increased availability of birthing centers and accredited midwifery. A central concern with the use of intervention in childbirth is termed 'the escalation of intervention,' when one intervention strategy ultimately leads to another, and another, and so on. For example, the apparently innocuous use of an epidural for pain management in labor has the ability to slow down and even cease natural labor, which ultimately leads doctors to pursue other strategies, such as Pitocin, breaking of the waters and, in more extreme instances, even cesarean delivery.

Much less attention has been paid, however, to how the same concept, the escalation of intervention, applies to medical intervention (here broadly construed as both prenatal testing and procedures) prior to labor and delivery. For example, a seemingly harmless and ordinary twenty-week ultrasound can lead to further, more invasive, genetic testing; amniocentesis; increased monitoring of the pregnancy; and early delivery. In this chapter I will investigate how the same concept of escalation of intervention in labor maps onto medical intervention in pregnancy through a narrative exploration of how one healthy pregnancy was inaccurately deemed high-risk. Attention to the narrative, and to the escalation of intervention in pregnancy in

general, will raise two epistemological concerns: first, I will explore questions about the value and perhaps unwarranted privilege of certain kinds of knowledge over others, and whether it is always better to have such knowledge, second, I will address questions about how epistemic authority is distributed between pregnant women and their healthcare providers and how this distribution impacts the value we place on certain types of knowledge.

I will argue that epistemic authority is given to the physician and biomedical/scientific ways of knowing in pregnancy and that such knowledge is given unwarranted privilege not just in the medical community, but by society at large. This privilege and priority serves to epistemically undermine women and their knowledge and control over their own pregnancies.

One relatively unnecessary and relatively unquestioned procedure that has become quite commonplace in prenatal care is that of the twenty-week ultrasound. While frequently assumed by women and families to be an exciting opportunity to "meet" baby, the procedure itself is actually a sophisticated test for a number of congenital or genetic abnormalities. Only women who are at elevated risk for certain conditions detectable through ultrasound *need* this exam. Yet it is almost universally offered in the United States, even to women who choose midwifery as a less-medicalized route for care during their pregnancies.

As I watched the screen breathlessly during the exam trying to discern the different body parts recognizable to me, the narration from the ultrasound technician slowly tapered which, at first, went unnoticed, until finally the room was silent with the exception of deafening mouse clicks freezing and unfreezing images on the

screen. I looked from the screen, to my partner, to the technician and back again, reading appropriate worry from each. Finally, the technician excused herself to summon the doctor. The doctor, one I had not yet met, took his position at the machine and ran the wand over and along my swollen abdomen, without a single word. He shut off the machine and began, "well, here is what concerns us…"

My ordinary level-three ultrasound had revealed three markers of Down syndrome. The markers detected included a thick nuchal fold, an echogenic bowel, and choroid plexus cysts, all of which were conditions that I had never even heard of. I was told that, alone, these markers didn't indicate any problem with my baby, but together, they increased the likelihood quite dramatically that the baby would be born with Down syndrome. Because I was so young, I had not elected to do any of the screening tests for genetic defects earlier in the pregnancy, but now, I was urged once more to have my blood drawn in order to discern the likelihood of Down syndrome from yet another measure. I hastily agreed. I quickly submitted to taking tests I had intentionally chosen not to just weeks prior. My reasoning not to take the tests initially had been quite simple: it was more likely I would find out I was at elevated *risk* for a condition than it was that the baby actually had it. I simply didn't want to worry. Before I knew it I was in the car on the way home wondering what to tell my friends and family—who to tell, even.

The twenty week ultrasound has become an assumed, if not required, diagnostic test in pregnancy. It is used to detect structural abnormalities of the fetus, the position of the placenta, and a myriad of other details about the pregnancy that are not discernable from the exterior of a woman's womb or by direct report from the

woman herself. They have been, for the most part, embraced by women as a chance to have a visual manifestation of their fetus, even in uncomplicated pregnancies. They are performed at twenty weeks, late enough so that measures of fetal growth and placental position are at least moderately relevant for projections of how the remainder of the pregnancy and labor will go, and early enough so that if abnormalities are indeed detected, something can still *be done* about them. Here, the expression 'to do something' means, almost always, to do further testing on the mother and the fetus, and, in some cases, to actually perform surgery on the fetus, prepare for surgery after birth, prepare the family for raising a child with a disability, or to terminate the pregnancy. A twenty-week ultrasound is generally not described to an expectant mother in this way, however.

The desire to know certain things about the baby (e.g., his or her sex) has relegated questions about the value of that knowledge to the backseat. The questions women could be asking of the pregnancy regarding the epistemic and ordinary aims of at their prenatal care include: what exactly am I looking for with this procedure, and what are my options if something abnormal is found? Here the problem may be that, while the physicians are not exactly pulling the wool over the eyes of mothers, they have neglected to inform them of the emotional and epistemic risks involved in the procedure, or to have urged them to consider whether these risks are meaningful to them. This indicates disregard for the epistemic status of pregnant women by physicians and medical norms. These are questions that need asking *prior* to this type of epistemic behavior, as a matter of appropriate reflection on our epistemic tendencies. Yet if women elect not to pursue an ultrasound for these reasons, partners

and other family members may still influence them to do so because it enriches *their* experience of the pregnancy.

There are a number of general worries about the use of ultrasound technology in pregnancy worth exploring. These worries concern what it does to our ideas about the mother and the fetus, as well as what it does to the budding relationship between mother and baby. Ultrasounds turn the mother into something to be looked *through* in order to access information about the fetus. Ultrasound technology works by making the mother invisible in order to come to know things about the fetus. This fact subsequently results in an understanding of the fetus as extractable from, or independent of, the mother—a serious ontological error. Depicting fetuses themselves as somehow isolatable from the context in or conditions under which they live is understandably troubling and not only influences the relationship a mother has to her unborn child, but likewise has impacted the way individuals standing on the outside of the pregnancy come to understand pregnancy and the fetus in general. Women can begin to consider the experience of seeing their fetus on the screen as somehow more enlightening, more personal, more meaningful, more *real* than the *ordinary* experiences of pregnancy—such as quickening—the experiences only available *to her*.

Here there is a real worry about potentially undermining a woman's special access—special knowledge—she has to the pregnancy as the sole person actually experiencing the *being pregnant*. There are many things that are available only to the woman, or via a direct examination of her, or through her own report; for example, the activity or movement of the fetus can be felt by the woman as early as sixteen

weeks gestation. Additionally, the position of the fetus in the womb can be detected by manual manipulation of the exterior of a woman's abdomen or even through her own sensation (and here it is worth noting a potentially helpful role for experts: by helping her interpret her sensations). How engaged the fetus is in (how far its head has dropped into) the pelvis can be determined externally as well, which is a useful indicator of the commencement of labor. Fetal growth can be measured by the height of the fundus.

For all of these reasons, ultrasounds used to merely determine the position or patterns of movement of the fetus in a healthy pregnancy are easily replaceable by the verbal reports from and direct examination of the person who is in the best position to know these things, the person carrying the baby inside of them. When an ultrasound is used to detect abnormalities in the fetus what serves to replace the pregnant woman is probabilistic information about risk. One might argue, then, that ultrasound use generates knowledge that is preferable to probabilities. Yet ultrasounds themselves are imprecise and so too only give us probabilities. Their indications are not exact and even in the most seemingly obvious instances there is still room to err.

A quotation from Barbara Katz-Rothman serves to jumpstart our analysis of the epistemic role of this medical technique:

> The doctor sits between mother and fetus. He turns away from the mother to examine the baby. Even the heartbeat is heard over a speaker removed from the woman's body. The technology that makes the baby/fetus more "visible" renders the woman *invisible*…The direct relationship to the baby within them, the fetus as part of their bodies, is superseded by the relationship with the fetus on the screen. The television image becomes more real than the fetus within; it is that image to which they "bond"; it is that image they hold in their minds as they feel their babies move. ("Tentative Pregnancy" 113)

The way in which an ultrasound can be interpreted as a bonding experience, the way it is traditionally interpreted, is quite baffling when viewed in this light. In a sense, the child has never been further away from its mother than it is at the moment of an ultrasound. More rightly, the ultrasound ought to be viewed as a bonding experience for family members or friends other than the mother, the people who do not get to experience such a direct relationship with the new baby. This is a potential explanation as to why ultrasounds are depicted as unprecedented opportunities to bond with baby: because they are so for fathers. The knowledge gained through ultrasound use when no complications arise, can replace the "knowledge" women had prior. What is meant by knowledge here is perhaps something more like "conception" or "image." The terminology exchange functions as something more than a semantic game. Imagery and individual conceptions ought to be considered epistemic goods in their own right and something independent is lost when these images and conceptions are so readily replaced by what is generated by an ultrasound machine and deemed "knowledge."

The worries raised by ultrasound use in pregnancy directly related to our present discussion are twofold: first, ultrasounds have become so commonplace they are virtually unquestioned by mothers and health care personnel. Rarely do women elect not to have ultrasounds, and when they do, they are often faced with opposition by their doctors, midwives, fathers and other family members. In all of the pregnancies and labors that turn out to be uncomplicated, these ultrasounds are unnecessary. Of course it is impossible to know beforehand that an ultrasound examination will turn out to be unnecessary; however, the choice of whether or not to

perform one should always be left up to the mother in the form of an overt and explicit decision, not just in having the (unknown) right to refuse the procedure.

Giving her critical information about the *epistemic* risks of routine ultrasound use validates the authority a woman has to make decisions about her own body, her own pregnancy, and her own epistemic standing, by allowing her the opportunity to consider how valuable the probabilistic data gleaned from ultrasound use about the fetus and the pregnancy is to her. Denying her the opportunity to make an overt decision about whether or not to have an ultrasound unduly privileges the kind of knowledge available through this technology and, in so doing, indefensibly elevates the epistemic importance and presumed superiority of empirical, biomedical data.

The second worry relevant to our main concern is that ultrasound technology, though highly advanced, is not a diagnostic tool; it is merely investigative. Thus, if an ultrasound reveals something unusual, the only course of action indicated is to *do more*. This was the case in my own experience: because the twenty-week ultrasound indicated a *likelihood* of Down syndrome, the next step was to determine whether or not the baby was indeed suffering from the condition with some higher degree of certainty (although still not with absolute certainty). The only way to determine this was via amniocentesis. After scheduling both the amniocentesis and a meeting with a genetic counselor, I came home to a freshly painted nursery, a box containing a crib I intended to build that weekend, a baby name book. I decided not to talk names. I decided not to put together the crib. I decided to tell people about the amniocentesis, and, if the test came back positive for Down syndrome and I decided to abort, that I would tell my friends and family that I miscarried as a result of the amniocentesis.

"Seeking and waiting for information changes the pre-information stage of pregnancy, creates what I think of as a "tentative pregnancy." it incorporates the issue of abortion right into the route to motherhood and institutionalizes the conditionality in motherly love" (Rothman, "Tentative Pregnancy" 85).

The talk of abortion, though, was introduced by the doctor who spoke with me right after my ultrasound. She came in to explain the findings of the doctor who oversaw my ultrasound. Terminating the pregnancy hadn't even crossed my mind until she indicated it as an option for dealing with a positive result from the amniocentesis, saying "we can take care of that for you too."

My life was immediately put on hold. All of my planning, all of my excitement soured. I went from talking about "when the baby comes" to "if the baby comes." I went from collecting items for the baby to collecting receipts for the items I already had. I went from worrying about diaper changes to worrying about changing diapers for the entirety of my child's life. This expectant, paused state of being is precisely what Rothman means by the tentative pregnancy. Rothman believes that the practice of amniocentesis for genetic screening puts mothers and families into a detached and weary relationship with their developing fetus; a relationship characterized by a sense of unease and uncertainty. This kind of relationship can cause a woman to experience some of the most exciting happenings of a pregnancy, such as the fetus's first felt kick, with anxiety and stress—a way markedly different from the way women not waiting for results from an amniocentesis to come in experience these events ("Tentative Pregnancy" 85).

The decision to have amniocentesis and the related (but not fated) decision of whether or not to terminate the pregnancy if the results were positive collapsed onto one another for me. I barely thought about the amniocentesis. It never occurred to me to consider turning down an invasive, risky, and painful procedure, even after my blood tests returned indicating a much lower chance of any problems with the baby. There was, however, no question for me. Similarly, there was seemingly no question for the doctors or the genetic counselors we spoke with. I would have the test done. The urgent and obvious nature of the affirmative answer to the question of whether or not to have further testing is indicative of the way in which a compulsion toward knowledge has influenced the medical management of pregnancy. The question of the value of knowing versus not knowing information about a pregnancy that is available through medical means is, in many ways, assumed to be answered by the medical establishment, and, predictably, answered in favor of the value of that knowledge. The issue of the presupposed value of medical knowledge to in our discussion will be returned to at the close of the chapter.

When I finally began to separate out the questions about amniocentesis and termination and more intentionally turn to the latter, it seemed, to others, as though that decision, too, was an obvious one. To my partner, to my sister, to my mother, the event of a positive result was the same as a positive answer to the question of whether the pregnancy should be terminated. I had (excitedly) considered the fetus to be "the baby" up to that point. Suddenly, I was back to talking about "the pregnancy" instead of the baby—the language used prior to conception. I began to portray my experiences in light of this new way of talking, this new information. Rothman writes,

"The problem, or one of the problems, with the technology of amniocentesis and selective abortion is what it does to us, to mothers and to fathers and to families. It sets up a contradiction in definitions. It asks women to accept their pregnancies and their babies, to take care of the babies within them, and yet be willing to abort them" ("Tentative Pregnancy" 6).

For me, the genetic counseling and the amniocentesis coincided. I met with the genetic counselor who took a family history (Down syndrome *is not* hereditary) and advised me to have the amniocentesis. Ultrasound is used while performing amniocentesis so the doctor can discern the best place to insert the needle and draw fluid with respect to the position of the baby and the placenta. The doctor chose, in my case, to push the needle directly through the placenta to draw fluid. This decision made the procedure more difficult and more risky. During the procedure, I watched the baby squirm and wriggle on the television screen. I watched the needle penetrate her sanctuary. They finished the procedure by switching the machine to its three dimensional mode and printing a picture of the baby—or not. They told me it was a girl. Following the amniocentesis, the doctor recommended that I schedule a subsequent ultrasound to discern whether or not the choroid plexus cysts had resolved themselves. Several days later, I received a phone call from the genetic counselor. The baby did not have Down syndrome nor any of the other genetic abnormalities detectable from the tests involving amniotic fluid. That evening, a name was chosen for my baby girl.

At six months gestation, I came back in for the ultrasound to determine whether the choroid plexus cysts had resolved themselves. They had. The ultrasound

technician, however, light-heartedly mentioned that the placenta looked "sparkly," by which she meant that the placenta appeared to be calcifying, or dying, more rapidly than it should be. The placenta, normally depicted as fairly dark on the ultrasound screen, was adorned with a coat of little white flecks, indicative of advancing gestational age. At my appointment with the obstetrician (the same obstetrician who introduced the language of termination several weeks previous), just after my ultrasound, the tone changed. I was urged to schedule weekly biophysical profiles and told that it was likely that they would need to deliver the baby early, since the ageing placenta was not going to sustain her for the duration of the pregnancy.

My pregnancy had turned from something joyful and exciting (albeit nauseating), to something anxiety-ridden and disheartening. Every week, for two months, I rode two busses to get to the doctor's office, careful not to exert myself too much for fear of depriving the baby of oxygen, careful not to slip and fall on the December ice, to lie down on the table in the ultrasound exam room and watch my baby kick and squirm, swallow and expel the fluid that surrounded her. Every week the placenta, to them, appeared worse and worse. Every week it took a little longer for her to achieve all of the tasks she was meant to accomplish in the allotted 30 minute period. Every week I left feeling more anxious, more fearful, that something would happen to her without my knowing it. I wanted to constantly be able to watch her on the screen. I wanted assurance that she wouldn't slip away from us in the days between my visits. Eventually, I got just that. The doctors decided that weekly exams were not sufficient, and asked me to begin coming in twice a week. The only time I felt reassured that she was indeed alive and well is when they told me so. Every time I

felt her squirming or kicking I worried it was too frequent or too far between, as both were indicative of a problem.

My body had turned into a treacherous place for a baby. It was as if, while I was alone with her, she was constantly in grave danger. The mere status of being inside of me put her unnecessarily at risk. She was only safe while being observed by the doctors, by individuals who could interpret her actions and translate them back to me. I was told that passing a biophysical profile was "good for 48 hours" meaning that no harm would be expected in the 48 hours following one of these exams. This, of course, felt as absurd as it sounds—but I was reassured again and again that it was so.

In the last few weeks of my pregnancy the weather turned very cold. I was happy for the excuse to curl up on the couch and closely monitor the baby's routine in my belly. I ventured out only for groceries (lots of them) and doctor's visits (lots of those, too). Finally the doctors decided that we should "come up with a plan" for her arrival. I was told that having one would relieve my anxiety, a complaint I was naive enough to mention when the doctor uncharacteristically asked me how *I* was doing. The plan they came up with was to do a second amniocentesis to test for lung maturity at thirty-six weeks gestation and, in the event that the results indicated maturity, to induce labor. The appointments were scheduled and, in a way, doing so did indeed alleviate some of my worries. I had an endpoint in sight. I only had to keep her alive for a few more weeks and, once she was out of me, she would be *safe in the doctor's arms*. I started worrying about lung maturity rates and induction procedures.

I read up on premature babies, crossing potential hazards off my list as the pregnancy extended into thirty-four weeks, thirty-five, thirty-six.

> But are women enemies of fetuses? Women, in fact, do not refuse such procedures nearly as often as they should…for most women, in the course of a wanted pregnancy, the fetus becomes real, precious, treasured. The overwhelming majority of women accept gratefully the cesarean sections their doctors offer—believing that it is best for the baby, even when the current data show quite clearly that probably three out of four cesarean sections in America are not necessary. (Rothman, "Recreating Motherhood" 167)

The day of my scheduled amniocentesis and potential induction finally arrived. The ultrasound technician completed one final biophysical profile and printed out Carlin's last ultrasound photo, a barely visible profile of her giant foot. At this point, we had about thirty of them. My experiences of the moments leading up to her birth were so different from what I had imagined a mere eight months previously. The doctor entered the room and began setting up for the amniocentesis. Because I had had one before, I started to worry about the pain of the procedure. Then I started to worry about the pain of childbirth.

Amniocentesis is considered to be more risky to a pregnancy earlier on. An amniocentesis is rarely done prior to twenty weeks because at any time sooner, a sufficient volume of amniotic fluid is not available to draw in order to run tests without risk to the pregnancy. The primary risk from amniocentesis is not, as you might expect, damage to the fetus but, instead, the induction of labor. The later into the pregnancy an amniocentesis is performed, the more likely it is that the fetus will survive if labor is triggered. At thirty-six weeks the risk of inducing labor was not as serious as it had been at twenty weeks. For this reason we moved on without hesitation.

Again, because of its prominent position, the doctor decided to go through the placenta to draw fluid. After several minutes of trying, the doctor removed the needle from my belly and I finally glanced back up at the screen. A rush of fluid was visible to me and, as the doctor hastily edged out of the room, I asked the ultrasound technician what I was seeing. "Blood," she answered, and through the doorway we heard the doctor's voice over the phone ordering a stat cesarean section. The needle had ruptured the placenta, and my blood was rushing into the amniotic sac. The doctor returned to the room, along with a nurse and a wheelchair, hurriedly explaining what had happened, and that the baby needed to be delivered urgently.

As I was rushed through the hallways connecting the office building and the hospital, for the first time in several months I felt inexplicably tranquil. Here, the life of my baby was acutely at risk by the hand of my own physician and, instead of feelings of fear, I was entertaining a sense of relief. I knew that, in a matter of moments, she would be safely in the world—no longer in a constant state of peril.

Because of the damage done to the placenta, there was no hope of natural birth, nor even induced labor. Instead, preparations were made for an emergency cesarean delivery. Rothman writes,

> Cesarean section is one of the most common operations performed on women, but it is rarely done to save the life or the health of the mother. Much more commonly it is done in response to fetal indications because obstetricians, rightly or wrongly, believe that the laboring uterus is potentially dangerous to the fetus. ("Recreating Motherhood" 167)

In my own case, it was not made at all clear to me how medically necessary the operation truly was. I had read about, and heard about, the procedure but was completely unprepared for what came next. After donning the smock and enduring a humiliating shave from my nurse I was separated from my family. I walked into the

operating room, trembling. The room was bright, windowless, and cold. I sat on the bed and leaned forward so they could administer the anesthesia into my spine. As I started to become numb I was situated into a supine position with the lower half of my body completely exposed to everyone in the room but myself—a sheet erected to further separate me from what was going on to create a sterile field. My arms were strapped down and I could feel nothing but cold, the cold of the air on my skin, the cold of the anesthesia working its way up my waist, the cold of the saline winding its way through my veins. I wondered if the baby was cold too. Adrienne Rich writes,

> "…but women are now asking what psychic effect a state of semihelplessness has on a healthy mother, awake during the birth, yet prevented from participating actively in delivery. No more devastating image could be invented for the bondage of woman: sheeted, supine, drugged, her wrists strapped down and her legs in stirrups, at the very moment when she is bringing new life into the world." (170-171)

They started cutting. I couldn't feel the cuts, but I could feel the pressure. I could tell they were doing something to me. I could tell they were doing things to me I would not be okay with if I could witness it. I watched the clock; I prayed that they would slow down. I started to cry. The anesthesiologist said he would give me something to calm me down. They delivered my baby and, after weighing, washing, and drying her, they showed her to me then quickly took her away to be monitored. A few minutes later, they called to me from the other side of the sheet and declared about my placenta: "it looks good—except for the abruption!"

In another depiction of delivery, this time of a vaginal delivery, I find echoes of these same horrifying descriptions of women no longer in control of what is happening to their bodies:

> certainly a woman who was unconscious, semistupefied, amnesiac, or simply numb from the waist down cannot have experienced giving birth as an accomplishment, something over which she had no control. But what of the woman who is encouraged in childbirth-preparation classes to see herself as a member of a "team" delivering

> her baby? Though she may help and watch in a mirror, she is not the primary actor. Positioning and draping her in such a way that she cannot directly see the birth, not allowing her to touch her genitals or the forthcoming baby, tells the mother that the birth is something that is happening to her or being done to her, not something she herself is doing. The birth is managed, conducted, by the other members of the team, those who are telling her what to do, and physically manipulating her and her baby. (Rothman "Giving Birth" 177)

There was something fitting in the fact that Carlin's birth had little or nothing to do with me. I was neither an active participant, nor particularly informed about what was going on. From the moment that I had my twenty week ultrasound until the moment I was released from the hospital, Carlin was cared for and managed by someone other than me. Her first thirty-six hours in this world were characterized by the dim lights and constant beeping of the NICU, difficult IV placements and a delirious mom hovering over her plastic container. Diapers were changed and weighed by nurses, food was administered intravenously. She was finally released to my care only to be hovered over and eventually removed from my room on account of "low body temperature." Later I was told by our pediatrician that the best remedy for low body temperature in a newborn is skin-to-skin contact with the mother, not the warming lamps they lay infants, like french-fries, underneath. Breastfeeding sessions were observed and critiqued by lactation consultants. When we were finally released from the hospital, 24 hours passed in a dreamlike haze before Carlin was readmitted to children's hospital on account of complications stemming from her premature birth and the ingestion of my blood which resulted from the ruptured placenta. Even after being taken from me, delivered to supposed safety, antibodies from my blood that had entered her blood stream were attacking her and preventing her from thriving. I was endangering her from a distance, even.

She spent the next month in a world she shouldn't yet have been in, losing weight, suffering from jaundice, having her heels poked, with a medicated mom recovering from a surgery she needn't have been subjected to. Carlin's premature delivery and difficult first month in the world were the direct result of an over-managed pregnancy—a pregnancy characterized by fear and anxiety, observation and intervention, and the undermining of the confidence of a mother and the developing relationship between mother and child.

To reiterate the way in which this story can be adequately understood through the framework of the escalation of intervention in pregnancy, all we need to do is briefly recount how each intervention procedure was necessitated by the one prior. Carlin's tenure in the NICU was necessitated by her premature delivery. Her premature delivery took the shape of an emergency cesarean section which was the course of events dictated by the placental abruption caused by an amniocentesis to check for lung maturity at thirty-six weeks. The amniocentesis for lung maturity was the decided endpoint for a series of biophysical profiles occurring weekly, and then increasing in frequency to twice a week. The biophysical profiles were ordered after the detection of calcification of the placenta during an ultrasound to check for the resolution of choroid plexus cysts. That ultrasound was ordered following an amniocentesis to test for genetic defects—genetic defects which were suspected based on the markers detected during the ordinary, albeit unnecessary twenty-week ultrasound.

While it is acknowledged that hindsight is always twenty-twenty, it should be pointed out that the only test that would have revealed a problem with Carlin was the

botched amniocentesis at thirty-six weeks to test for lung maturity. No amniotic fluid was successfully drawn during the procedure, but the placental abruption caused by it necessitated an early delivery regardless of whether or not her tiny lungs were prepared to take in air. This abruption, recall, was the only problem they noted with the placenta following delivery. That is, there was no evidence of premature placental ageing, or any other condition that could have caused harm to the baby. What did end up causing a problem for her was the presence of my blood in the amniotic fluid, blood that was introduced as a result of the unsuccessful amniocentesis.

What really struck me as I gazed down at my average sized infant—the giant of the NICU—was that she was the product of a completely healthy pregnancy. The only reasons I could come up with to explain the tubes and monitors coming off her had nothing to do with me. Acknowledging this fact, standing in stark contrast to everything I had been told and everything I felt up to that point, immediately relieved the cognitive dissonance built up inside me by wanting so badly to take care of my daughter and yet believing that I was putting her in danger just by having her inside of me.

I want to briefly make the case of how the concept of "escalation of intervention" can be used in pregnancy just as it is in labor and delivery. Recognition of the risk of an escalation of intervention during labor and delivery is relatively uncontested. Examples of how this story can go include the use of epidurals which can slow down the rate of natural contractions, oftentimes resulting in the use of labor medicine to speed up or re-start labor, or that being made to lie on a hospital bed in the supine position reduces the efficacy of contractions and can lead to the use of

forceps or vacuum extractors to assist in the birth of the child. One intervention strategy, in particular, exemplifies how the escalation occurs:

> the artificial induction and stimulation of labor, widely resorted to in the United States, produces longer, stronger contractions with less relaxation span between them than the contractions of normal labor. This in turn leads to the use of pain-relieving drugs; as so often, medical technology creates its own artificial problem for which an artificial remedy must be found. These unnaturally strong and lengthy contractions can deprive the fetus of oxygen, while the analgesic drugs interfere with its respiration [after delivery]. If labor in the United States were induced only in cases of medical necessity, only about 3 percent of births would be induced (Rich, 178).

The successful mapping of the kinds of cause and effect relationships characteristic of the escalation of intervention in labor and childbirth onto the case of pregnancy indicates that the concept applies to issues of pregnancy as well. One worry that might be raised here is that the real issue in both of these cases is not a genuine escalation of intervention; instead, it is the mere medicalization of pregnancy and childbirth that is troublesome. I hope it is clear from the narrative example, as well as from the quotation from Rich that there is something more menacing at work here than the simple fact that pregnancy and childbirth have been infiltrated by the medical institution and have become considered *conditions* requiring *treatment*. The depravity of this understanding of pregnancy and childbirth is not being denied here; however, it is not my purpose to argue that medical intervention is malum in se.

In childbirth, aside from the techniques used to speed up or render labor painless, there are also a number of monitoring technologies in common use, and these raise the sorts of specifically epistemic concerns that are my focus. Fetal monitors, for example, are commonly used in hospitals to detect the heart rate of the fetus during contractions. They are a fairly new and now increasingly frequently if not universally used during delivery at hospitals or birthing centers. As the use of fetal monitoring has increased, coincidentally, so has the instance of emergency

cesarean delivery. So here we have an example of the kinds of technologies that we use to answer some of the questions we have about the state of a pregnancy or the status of a fetus during labor. Yet, the accuracy of the answers provided by these mechanisms are undeniably in question. Fetal monitoring has the potential impact of raising concerns about the status of the fetus during labor and delivery when none are necessary and, therefore, can initiate undue intervention in the process of labor. Similarly, as we have seen in our narrative example, an ultrasound might wrongly indicate concerns about the intrauterine environment (e.g. a prematurely ageing placenta), pressuring doctors to deliver the baby "to safety."

Even if we bracket the possibility for the kind of harm set in motion by these information-seeking techniques suggested above, the question arises as to whether harm can come from the mere information seeking in the first place. In other words, if we grant the possibility that procedures like screening for abnormalities of the fetus with ultrasound were 100% accurate in predicting problems, would there still be a concern about the use of ultrasound, the asking of these kinds of questions, in the first place?

In order to get clearer about *this* question, we will begin looking at an example drawn from a different area of medicine to making the case for the applicability of the notion of escalation of intervention to intervention in pregnancy: the comparison with screening men for prostate cancer. The worry raised by prostate cancer screening is the course of events that can be set off by a false positive result (in many cases, a false positive result in an individual who was not at high risk in the

first place, a possibility that should call to mind the concern about Down syndrome in the low-risk case considered earlier). Barry writes that,

> Serial PSA screening has at best a modest effect on prostate-cancer mortality during the first decade of follow-up. This benefit comes at the cost of substantial overdiagnosis and overtreatment. It is important to remember that the key question is not whether PSA screening is effective but whether it does more good than harm. For this reason, comparisons of the ERSPC (European Randomized Study of Screening for Prostate Cancer) estimates of the effectiveness of PSA screening with, for example, the similarly modest effectiveness of breast-cancer screening cannot be made without simultaneously appreciating the much higher risks of overdiagnosis and overtreatment associated with PSA screening. (1351)

The trouble with prostate cancer screening is that, when required of men regardless of their susceptibility or risk level for the disease, it will result in overdiagnosis and over treatment. These treatments are wide ranging in terms of their invasiveness and severity. Once something is diagnosed, however, whether accurately or inaccurately, there is a call for action on the part of the physician, and the course of action resulting from diagnosis is rarely questioned by the patient. Similarly for medical intervention in pregnancy. The use of indiscriminate investigative procedures, such as twenty-week ultrasounds, can result in the overdiagnosis of problems with the fetus. This, of course, is particularly worrisome in the case of patients who are not at risk. Once the alarm has been sounded, mothers and doctors alike are compelled to continue down the path of diagnostic screening and intervention. It would be difficult, if not impossible, to turn away from the risk of Down syndrome, or, even perhaps more so, a risk of the baby not thriving due to a prematurely ageing placenta. Once the problem has been identified, whether correctly or incorrectly, a path for action has been laid down for mother and physician alike.

Here is where the analogy between intervention in pregnancy and PSA screening may begin to break down. If we were able to come up with a diagnostic

procedure that were 100% accurate in detecting prostate cancer, would the worry about PSA screening resolve itself? The answer to this question might seem to be an obvious 'yes.' The primary concern in the case of PSA screening is that, in the event of a false positive, a chain of events is kicked off leading to unnecessary medical procedures including, in severe instances, the complete removal of the prostate in unaffected men. There seems to be nothing wrong with wanting to know if a man has prostate cancer; in fact, it seems an undeniably good thing to be able to answer that question. A more nuanced answer to this question, however, would acknowledge that a man can live with the diagnosis of prostate cancer for, in many cases, several decades before suffering any adverse symptoms from the disease. Indiscriminate PSA screening as it currently stands, then, leads to a significant number of false positives and the identification of cases in which the man will experience no effect from his condition, yet indeed has it. Even if we control for error, we may still be subjecting otherwise healthy men, men who are ultimately more at risk of death from something other than low-grade prostate cancer to unnecessary, invasive tests and treatments. And yet there is an overwhelming desire to know in these cases, regardless.

In the cases of patients like these, the answer is more likely to mimic the answer we get when we ask the question of diagnostic testing in pregnancy. Indeed, the question remains in the case of intervention and diagnostics in pregnancy. If we could develop a diagnostic technique that were 100% accurate in detecting things like Down syndrome, or an ageing placenta, would the worry dissolve? The answer, I think, is clearly 'no.' There is, in the case of pregnancy, something troubling in the

very *asking* of these questions. A certain kind of information or knowledge about the fetus has come to be valued over another.

How is it that we have come to be asking the questions that we are about pregnancy? Why do we need to know if the baby is a boy or a girl, healthy or unhealthy, upside-down or right-side-up? In the case of some of these questions, the answer is obvious: because we can *do* something about it. For others, the answer is not so obvious. For others, the answer might be something more like, because we *can know*. To me, it is not at all clear why knowing, in the case of genetic testing, is any better than not knowing, and, moreover, why knowing in this privileged, empirical and scientific way is better. There is a certain kind of epistemic imperialism at play here. This epistemic imperialism sets out what the important questions are to be and sets out the ways in which we are to go about answering those questions. The kinds of questions we are asking and the kinds of answers we are getting are driven by, created by, the kinds of technology we have and not, instead, by a need we have for any particular kind of information. This undeniably sets up a hierarchy of knowledge, privileging the information that is technologically available, making it seem more important when, really, it is only more available.

Another way of thinking about the way knowledge operates in pregnancy and childbirth is the trendiness of labor and delivery. With each of my three children, recommendations, practices and procedures, and testing and information gathering have gone through significant changes. For example, with my third child (a scheduled C-section) I was required to wear a fetal monitor for 2 hours before delivery. It is not clear what two hours of fetal heart rates tell you when you are having a delivery all

along, yet the technology is there and the information, wherever it goes or however it is used, is still collected. Everything from pacifier use to swaddling techniques have changed and each time this information is presented to me as the objective *knowledge* of how to care for my newborn. This is not to say that there is not important information, some of which is the product of scientific inquiry, that needs to be shared with new parents (e.g. the impact of shaken baby syndrome), but at some point intuition and individualized insight need to be acknowledged by doctors as additional epistemic goods.

I hope that the investigation into comparisons among childbirth, PSA screening, and pregnancy have left little question as to the appropriateness of the concept of escalation of intervention as it applies to pregnancy. Each of our approaches to making the case for the applicability of the concept has unearthed some serious worries about the harmfulness of such an escalation of intervention. Briefly, then, I would like to reiterate some of the potential harms caused by such escalation on the whole (as opposed to the harm caused by intervention procedures themselves) before turning to a recommendation for how to better manage the issue. The damage caused by the escalation of intervention begins with how it changes the experience of pregnancy for the mother.

Pregnancy can be and should be an exciting and positive experience for the mother. Pregnancy should be about developing a relationship with the fetus, about experiencing certain changes in your body and your life that are characteristically feminine (Hilden 100). *Pregnancy should be about a growing sense of confidence in yourself as a mother.* When medical intervention procedures are allowed to escalate

out of control, it changes the whole tone of pregnancy. It turns pregnancy into a medical crisis. It punctuates the felt flips and kicks of the fetus with fear instead of joy and anticipation. The escalation of intervention in pregnancy undermines the epistemic authority and control that the woman has over her pregnancy. When an individual's attempt to make meaning for herself is thwarted by a society's or an institution's incompatible understanding of an issue, Fricker deems it a case of hermeneutical injustice (155). She writes:

> When you find yourself in a situation in which you seem to be the only one to feel the dissonance between received understanding and your own intimidated sense of a give experience, it tends to knock your faith in your own ability to make sense of the world…[it] stem[s] most basically from the subject's loss of epistemic confidence. The various ways in which loss of epistemic confidence might hinder one's epistemic career are …that it can cause literal loss of knowledge, that it may prevent from one gaining new knowledge, and more generally, that it is likely to stop one gaining certain important epistemic virtues, such as intellectual courage. (163)

Two different, yet intertwined, claims that women have to knowledge about pregnancy, I believe, need to be disentangled here. On the one hand, the historical practice of midwifery and the techniques, approaches, and insights that have been passed down by women to women throughout human history which has been replaced by the modern, medicalized approach to pregnancy we are more familiar with today does indeed suggest that there is some kind of special access, some practical insight women have to matters of managing pregnancy (Rich 149). Even if we bracket this possibility, there is yet another kind of knowledge that women have access to that is or can be challenged by technologically driven ways of knowing about pregnancy; women who are pregnant, or who have been pregnant, have what is called experiential knowledge of their pregnancy and of pregnancy in general. This kind of knowledge has historically been disregarded yet it is unquestionably valuable, and has the potential impact of altogether shifting the way an individual sees the world, and

sees herself in the world (Shapiro 59). This kind of knowledge, however, is not meant to compete with or mimic the kind of knowledge available through information-seeking technologies used in pregnancy. At the same time, this kind of knowledge is indeed threatened by these technologies. In fact, this kind of knowledge takes a back seat to the kind available to the physician by looking *through* the mother, whether by needle or sound wave.

With these two distinct types of potential knowledge only women have about their pregnancies in mind, it is not the case that I am arguing that I—or any other woman—is in a position to know better than my doctors about the health and viability (or lack thereof) of my child in utero. What *is* being argued is that the preference for having the kind of knowledge available through medical diagnostics may be unfounded and the quest for this kind of information disrupts the course and experience of pregnancy. The privilege of and search for this kind of information about the pregnancy, however accurate or inaccurate the results, pushes aside the importance of the kind of insight a woman *can* have into her pregnancy, dramatically alters the way she experiences it, and depletes the sense of (and actual) control she has over how it unfolds.

In conclusion, I hope that through an examination of the narrative case and comparisons with PSA screening and labor intervention, the claim that the same concept of escalation of intervention in labor maps onto medical intervention in pregnancy has been grounded in adequate justification. Similarly, the attention to the narrative and to the escalation of intervention in pregnancy in general, has underlined several epistemological concerns: the value of relevant kinds of knowledge (e.g.,

technologically driven knowledge over intuition or experiential knowledge), whether knowledge is always better than ignorance and what circumstances would mitigate choices between the two, and how epistemic authority is distributed among pregnant women and their healthcare providers. With these epistemic concerns in mind in closing we ought to ask what might have been done otherwise, or whether we see any recommendations for the avoidance of raising issues like these in pregnancy.

In answering, a frequently quoted line from remark 308 in Wittgenstein's *Philosophical Investigations* comes to mind: "The decisive movement in the conjuring trick has been made, and it was the very one that we thought quite innocent" (103). While removed from its original context we can interpret this to mean that we should start asking questions sooner. It was at the twenty-week ultrasound, a procedure I excitedly anticipated and in no way scrutinized, that the ball began rolling in this instance of escalation of intervention. The very asking of the kinds of questions answerable by medical technology in pregnancy (the decisive move in the conjuring trick) can have, and has had, the impact of setting off a destructive chain of events—a sequence of questions, answers, and approaches, that have the effect of causing the kind of epistemic harm to mothers and to families explored in these pages.

Another way of approaching a solution is to avoid looking at knowledge as something abstract or abstractable from knowing agents, especially in the case of pregnancy. Here we are talking about two bodies; two bodies more interconnected than in any other relationship found in nature, yet trying to discern information about just one of them. It is important that we keep both features of the subject and the

object of knowledge in mind when we begin to analyze information seeking behavior. What features, then, do we need to include about knowers to make our theorizing about them productive and applicable?

Approaches to epistemology that suggest some possible features of knowers and knowledge relevant here include insights from the disciplines of feminist and virtue epistemology, especially the argument in feminist epistemology that features of the knower (in particular, the gender of the knower) are relevant in circumscribing cases of knowledge. In her essay, "Taking Subjectivity into Account," Lorraine Code argues that relevant factors concerning a subject's situatedness, such as race, class, or gender, ought to be considered in any investigation of what the subject can or cannot rightly be said to know. She writes, "…conditions that hold for any knower, regardless of her or his identity, interests, and circumstances, in other words of her or his subjectivity—could conceivably be discovered only for a narrow range of artificially isolated and purified empirical knowledge claims, which might be paradigmatic by fiat, but are unlikely so 'in fact'" (Code 191). She argues for what she calls an "epistemology of everyday lives" and urges that we turn away from artificially sterilized models of knowledge that steer clear of what she takes to be the highly relevant circumstances of located knowers (Code 192).

Code begins her argument with an assault on traditional "*s* knows that *p*" epistemologies for their (often implicit) assumption that '*s*' and '*p*' are merely place holders which can be replaced by any *s* or any *p*, and maintain efficacy. When you begin to scrutinize the kinds of things you substitute for *s* and *p*, however, such a schema loses its capacity to represent many natural knowledge claims. According to

her interpretation of such approaches to representing knowledge claims, it follows that: "If one cannot transcend subjectivity and particularities of its 'locations,' then there is no knowledge worth analyzing" (192). Only a narrow subset of human knowledge claims, according to Code, can be isolated and analyzed by an epistemology which does not attend to the subjectivity of the knower.

For Code, and for us, the location of the knower—his or her social identity, interests or desires, and circumstances of her situation—make it the case (or not) that some knowledge is desirable, undesirable, or even possible. As knowers we are not different from ourselves as patients or poets. What we can be said to know, what we set out to know, is limited, shaped, and driven by our location. Knowing is not something that we do apart from all of the other things that we do. Knowing is embedded in, constitutive of and constituted by our locations.

The implication of this wider view of ourselves as knowers for the resolution of the tension arising from supposing that knowledge can be harmful to us *as* knowers means that harm caused to us by the pursuit or acquisition of knowledge that influences our location also influences us as knowers. Knowledge or knowledge seeking that changes our relationship with our spouse, for example, changes us as knowers. It circumscribes what we can know, how we can know, if we should know, whether we want to know, and so on. It could be pointed out here that a consequence of this claim is that any harm could somehow be construed as an epistemic harm. However, I want to limit our discussion to epistemic behaviors that have this potential impact, not just any behavior whatsoever.

To sum up, then, the implication of the wider view of ourselves as knowers means that harm caused to us by the pursuit or acquisition of knowledge that influences our location also influences us as knowers. We have further limited cases of interest to those of harm caused by epistemic activity, but not necessarily epistemic activity of a malicious type. Having a narrow epistemic focus on collecting facts can cut us off from having a wider epistemic relationship with the world.

We are still left with the possibility of broadening what we mean by 'knowledge,' or increasing the kinds of things we consider to be epistemically valuable ends. Again, what we want to avoid is a depiction of knowledge that is somehow separate or separable from all of the other things that we do. Similarly, we want to avoid a narrowing of the epistemic, or the conflation of knowledge with epistemic good. In this chapter alone we have encountered many other ends that we might include in the realm of what constitutes an epistemic good: for example, intuition, meaning-making, experiential "knowledge," self-awareness (that is, discerning in advance what we might do with certain information and an ability to judge if we want that information to begin with), and a healthy skepticism of technologically driven knowledge.

Chapter Three: Nurses Know: How power and privilege influence nursing knowledge, work, and testimony.

This chapter investigates the role of epistemic imperialism (unduly privileging knowledge of a certain sort, and methods of achieving knowledge of a certain sort, over other available knowledge/methods) and power imbalances between physicians, patients, and nurses in how nursing knowledge is received, represented, and understood not simply the players immediately involved (e.g. the physician, patient, and nurses) but also by the general public. I argue that what nurses know, and the work that they perform is often rendered *invisible* to patients, physicians, nurses, and the general public by the function of these power structures and epistemic imperialism.

Nurses operate with three types of special knowledge: case (biomedical/scientific), patient (applied case knowledge), and person (biographical knowledge of the patient) and because they operate with patient and person knowledge rather than just case knowledge (biomedical/scientific knowledge), they are better able to care for patients in the face of ignorance about the biomedical/scientific knowledge than physicians are. Because nursing is a boundary discipline, in that it operates both in and between two very different realms of knowledge (the scientific/biomedical realm and the subjective/personal realm), much of what nurses are up to in their day-to-day tasks is unseen or unacknowledged by patient, physician, and public and is not even recognized by nurses themselves as constituting *work* (Stein-Parbury and Laischenko, 2007).

As an example of how this invisibility plays out, I operate with a very personal narrative (that of my pregnancy with my third child) as representative of the critical role nurses played in coordinating my care, navigating me through the healthcare system, and seeing me through multiple complications. These three tasks—the coordination of care, navigating the patient through the healthcare system (referring patients and guiding them through and often outside of the labyrinthian institutions in which they are engaged), and providing personal attention and care to the patient—constitute the bulk of the work nurses are doing on a day-to-day basis. These three types of work partake in multiple realms of knowledge (biomedical/scientific and subjective/personal knowledge) at issue here. And yet, it is only the last of the three (paying personal attention to and caring for the patient) which is generally seen as *what nurses do*.[1]

I argue that attention to epistemic imperialism and power imbalances in the healthcare system sheds light on the first two tasks (coordination of care and the assistance nurses provide patients in navigating the healthcare system). Attention to epistemic imperialism and power imbalances properly situates these tasks as recognizable *work* and highlights the relevant *knowledge* nurses operate with thus rendering it at least on par with the scientific/biomedical knowledge we have come to prefer as patients, healthcare providers, and members of the general public (Laischenko, 1997). Even with their work recognized as work and their knowledge recognized as knowledge, we need to push further and argue that: nurses are subjects of testimonial injustice: an instance where we do not count information gleaned from someone's testimony as knowledge without corroboration—corroboration achieved

by bending over backward to verify (or even undermine) that person's claims (Fricker, 2007).

Finally, it is only through examination of epistemic imperialism and power imbalances that we can begin to rectify these injustices suffered by nurses and, in so doing, improve our own understanding as patients and members of the general public of the importance of the work that nurses do and the knowledge that they, indeed, have. If nurses themselves cannot articulate their work as such, how will the knowledge of nursing work ever be disseminated? Therefore, attention to these epistemic issues is also central to nursing education.

In this chapter I will first explore the role of epistemic imperialism in the hierarchal structure of healthcare. I will demonstrate that because a certain type of knowledge is privileged over others, the knowledge nurses have and, therefore, the work that they do are rendered invisible. I will explore this invisibility and how it relates to the historical invisibility of women's work. I will use a personal example to demonstrate the invisibility of nursing work and knowledge. I will then demonstrate that the framework used for nursing knowledge has a general applicability the broader work of this dissertation. I will discuss the fact that, since nurses operate with these other sorts of knowledge, they are better able to care for patients than physicians in the absence of biomedical/scientific knowledge which has become so overvalued. I will also show that nurses' knowledge, because of the privilege for biomedical scientific knowledge, subjects them to testimonial injustice. I will then explore avenues for rectifying this injustice by putting nursing knowledge on par with biomedical/scientific knowledge. I will argue further that epistemology must inform

nursing education in order for nurses to adequately give voice to the importance of the knowledge they have and the work that they do, moving it out of the shadows and placing it front and center.

Epistemic Imperialism

Power imbalances in the healthcare system favor the physician. Nurses work in a layered hierarchy with physicians at the top, PA's, RN's, nurses, nursing aids, and hospital staff (lab techs, janitorial staff) at the bottom. Nurses, although they do a great deal of work, are not at the top of the hierarchy. Why is this the case? I believe it is the case not just for historical reasons, but also because of the privilege of the kinds of knowledge that physicians are after (biomedical/scientific). When one type of knowledge is privileged over another, it pushes the other types of things we can come to know to the side. So, in this case, privilege for lab results, CT scans, MRI imaging, x-rays, etc., pushes aside the patient's own retelling of their story—of what happened to them, and of how the disease/injury is impacting his or her life. (You might point out here that, if we are relying on these sophisticated scanning techniques, then aren't, we in some way epistemically privileging, say, the CT technician? While most technicians can indeed read their own scans, they are required to pass them along to a physician in order to give their own validated read.)

The function of the power imbalance influences the skewed preference for knowledge. This skewed preference puts much of the knowledge nurses have on a lower level than knowledge available through imaging/testing. This, in turn, puts nurses and their work on a lower level. It is both the power informing the epistemology and the epistemology informing the power. What I mean by this is that

the power structure keeps the epistemic imperialism in place and, at the same time, epistemic imperialism props up the power structure. Nurses are not in positions of power because the knowledge they have is not taken seriously, and because they are not in a position of power, what they say is not taken seriously.

I argue that what nurses know, and the work that they perform is often rendered *invisible* to patients, physicians, nurses, and the general public by the function of these power structures and epistemic imperialism.

Invisible Work

Caring professions, such as nursing and early childhood education are traditionally undervalued as they are inherently linked with women's work: the work of running a household. Caring for and feeding your husband and children, keeping the house clean, etc. are what women were once understood as doing, and any type of work that links up with caring in this same way has the risk of being rendered invisible in the same way traditional women's work has been rendered invisible.

The power imbalances in which women lived when housework was invisible mimic the power imbalances in the structure of the healthcare system. There was/is a hierarchy with men at the top, women and their work in the middle, and children at the bottom. This is similar to the hierarchy in healthcare with physicians at the top, nurses in the middle, and janitorial staff, etc. at the bottom. Because the power imbalances are informed by epistemic imperialism, epistemic imperialism influences these power imbalances. In the case of traditional women's work, surely women's knowledge of how to get household work done was undervalued as compared to a man's knowledge of how to get his own work done.

Because nursing is a boundary discipline in that it operates both in and between two very different realms of knowledge (the scientific/biomedical realm and the subjective/personal realm), much of what nurses are up to in their day-to-day tasks is unseen or unacknowledged by patient, physician, and public, alike, and is not even recognized by nurses themselves as constituting *work* (Stein-Parbury and Laischenko, 1997). Here we may start to see parallels between sexist, domestic life in which the women were both the visible care takers (preparing meals, tying ties) as well as the invisible care takers (keeping the home clean and spotless while the family is away during the day). Nurses and others may see their direct role of caring (administering medication, taking blood pressure, reporting to the physician) while missing the invisible work nurses are up to during their shifts such as keeping patient notes, talking with the patients under their care, talking with family, communicating problems to the physician, etc.

Narrative

My pregnancy started in mid-2013 with complication: After an IUD became imbedded in my uterine wall and needed to be surgically removed, I was prescribed progesterone only pills (or mini-pills) because I suffer from migraines and other forms of birth control pills which contain estrogen can actually exacerbate migraines. Progesterone only pills need to be taken at precise times: being off schedule for more than a few hours can result in pregnancy, and that is what happened in my case. Before learning I was pregnant I had engaged in behavior that was risky—in particular, I took taken prescription medication for migraine treatment that is relatively high risk to the unborn fetus. Although I learned of the pregnancy early

(because I noticed my headaches were not being relieved by ordinary measures, and unrelenting headaches had been characteristic of my previous two pregnancies), and none of these behaviors actually impacted the developing embryo, it was still deemed high-risk. It should be noted I received a category D medication prior to implantation (Depakote), for migraine treatment I was also still taking category C medications.

Category C medications are of several types. Some medications are classed category C because there is evidence in animals that at extremely high doses (thousands of times the therapeutic dose) can cause birth defects, low birth weight or other problems with the neonate animals. Others are category C because they have been shown to be unlikely to cause much harm to the fetus in humans. Even others are category C because they have no evidence for or against harm to the fetus.

Category D medications have been shown to increase the likelihood of harm to the fetus in humans. Category X medications produce harm in most cases. Category D and X medications are not recommended in pregnancy. Category C medications are often prescribed by OB/GYNs and other providers during pregnancy. Category D drugs are rarely used in pregnancy, but if the mother has a condition like epilepsy that, if she were to have a seizure, could cause harm to both herself and her fetus, then they may be prescribed. Category X drugs are not prescribed during pregnancy.

So the pregnancy was from the outset complicated with respect to the fact that I was on multiple medications which required monitoring and the coordination of care. The pregnancy shortly became yet more complicated: after missing a step, I twisted in an unusual way and tore multiple ligaments holding my pubic symphysis

together. I was not able to walk well, take stairs, etc. To address the injury, I was prescribed medication, went to see multiple other providers (orthopedics and PT) and told to "rest." A nurse at my OB clinic helped me find the appropriate kind of physical therapist and orthopedist for someone who is pregnant.

Yet, rest was difficult to come by while teaching and caring for two young kids. This injury occurred in April, and with a C-section scheduled for July 11th, I started counting down the days. As the baby grew, the pain became more severe. When the baby's head dropped into my pelvis, I could barely walk. As a result, they rescheduled the C-section for July 1st and our son, Abbey, was born that day. He was watched in the hospital by the nurses and physicians with great scrutiny to determine if he was experiencing withdrawal from any of the medications I was using during my pregnancy. He showed no signs of withdrawal in the hospital, and shows no ill effects to this day.

After Abbey was born I was alone with three children while my partner was away on a research trip. Despite help from family and friends, I was unable to take good enough care of myself to heal from the surgery and injury. I had severe pain and lost 30 pounds in 30 days.

When my partner returned in august I was finally able to get back to the doctor. After multiple visits, a CT scan, and an ultrasound, they finally found something that "backed up" my story of pelvic pain. They found a sack of fluid in my uterus. After being sent to the ER for pain, I came into the clinic for them to attempt to biopsy the fluid. Because of the pain, they were unable to do a manual exam, and the scheduled me for a dilation and curettage.

When I arrived at the day surgery center a week later, I was told I was not on the surgery schedule. I was adamant that they were mistaken. I asked to speak to the doctor who was (not) scheduled to do my surgery. She was unable to talk to me. I walked to my clinic and demanded an explanation. I was given the option of going home and coming back next week (not a viable option for me, given my level of pain and the fact that I had been fasting for 13 hours and weighed only 104 lbs) or waiting to see if they could squeeze me in to the schedule that afternoon. I opted to wait.

When they finally took me in for surgery, the anesthesiologist and her nurse told me that if at any time during the procedure I was uncomfortable, all I had to do was ask for full anesthesia and they would put me under. During the operation, I was in a great deal of pain. I cried out for help but was ignored by the anesthesiologist and her staff. I heard them order an anti-biotic and asked what those were for. No one answered me.

It was not until I was in recovery that someone explained to me what had happened: they had perforated my uterus during the operation with the curettage. This put me at risk of bleeding, infection, and increased the risk to my uterus for any future pregnancies, I was told.

Eventually, I filed a patient complaint for all that had happened to me. I still have not heard back from Fairview patient relations. I am on high doses of pain medication which impair my ability to focus, work, write, think, take care of my children, and drive.

So what was the role of the nurses in this narrative? *First,* any coordination of care between my neurologist, psychiatrist, and OB/GYN for managing my medication

was done by nurses. This meant that nurses from my OB/GYN had to call nurses from my neurologist and psychiatrist's office to get information about what medication I was on, okay medication changes made by doctors, etc. *Second*, nurses helped me navigate through the healthcare system when I became injured: helping me acquire referrals, finding the right providers, etc. *Third*, nurses helped me coordinate with my doctor when the C-section had to be rescheduled. *Fourth*, nurses were involved in the C-section, and were the primary people involved with my aftercare. *Fifth*, nurses watched the baby for signs of withdrawal and communicated their findings at shift change. *Sixth*, nurses helped me schedule an appointment when my partner came back to be seen for my pubic pain and bleeding. They also helped me coordinate the proper imaging that the doctors wanted. *Seventh*, they helped me make decisions about what to do when the pain became so severe (such as go into the ER) and ultimately schedule for surgery. *Eighth*, when the surgery was mis-scheduled, it was a nurse who coordinated my options and ultimately got me back on the surgery schedule. *Finally*, they helped me coordinate referrals to a pain clinic, endocrinology, neurology, and PT, as well as continue to help me with my patient relations complaint.

While it might seem like it is the doctors who work their magic and, say, order the proper pain medication for me or squeeze me into their schedule, it is actually a nurse laboring behind the scenes trying to get a physician to sign off on a pain-medication change. It was nurses who helped me in my hospital stay: monitoring Abbey closely, although he was fine, managing my pain post-operatively and post-Bolivia. It was nurses who held my hand through the D & C and ultimately explained

to me what happened with the procedure and how it had gone wrong. It was a nurse who managed my pain post-op. It was the coordination of nurses who got me on the proper pain medication regimen to keep my pain (somewhat) under control. And it is nurses who are guiding me through the system: to neurology, endocrinology, physical therapy, psychiatry, and a pain clinic.

These tasks dip in to both biomedical/scientific and personal/subjective knowledge. And yet, it is only one of the three: paying personal attention to and caring for the patient, which is generally seen as *what nurses do* (Laischenko, 1998).

I argue that attention to epistemic imperialism and power imbalances in the healthcare system shed light on the two tasks that went "unseen": coordination of my care and the assistance nurses provided me in navigating the healthcare system.

Attention to these two tasks demonstrates that nurses have knowledge—albeit testimonial knowledge, from the patients, that is important to the coordination of care, the expectation for outcomes, etc. If we don't know what someone does for a living or how much help they have at home or can reasonably be expected to get, then we don't know anything about their health outcomes. What I mean by this is that I can make prescriptions, for example, for someone to "rest." But if I don't know what they do for a living or what their home situation is like, how can I know they will actually be able to rest? I need to know certain facts about a person's life before I can begin to tell them what they need to do for their health. I need to know what they are capable of doing.

I argue that attention to epistemic imperialism and power imbalances properly situates the tasks nurses do that we don't acknowledge as recognizable *work* and

highlights the relevant *knowledge* nurses operate with thus rendering it at least on par with the scientific/biomedical knowledge we have come to prefer as patients, healthcare providers, and members of the general public (I will demonstrate why I believe this is the case shortly) (Laischenko, 1997).

Framework of Nursing Knowledge

Liaschenko and Fisher develop an interesting framework in nursing epistemology for the types of knowledge used by nurses on the job. It includes three primary types of knowledge: biomedical/scientific; patient knowledge; and person knowledge. These types of knowledge are connected by social knowledge.

Biomedical/scientific knowledge is the type of knowledge that nurses gain both on the job and in their schooling. It has to do with anatomy and physiology, different technologies used in patient care such as EKG's and ultrasound, and knowledge of pharmaceuticals.

Patient knowledge is understood by Liaschenko and Fisher as biomedical/scientific knowledge now applied to the case at hand. So patient knowledge has to do with monitoring how the patient is responding to therapeutic practices employed in their case.

Person knowledge, on the other hand, has to do with the patient in the context of their everyday life. It requires testimony from the patient regarding what kind of work they do, what their home life is like, what relationships and help they have, etc. Liaschenko and Fisher have reservations about the amount of person knowledge it is appropriate for nurses to have in a given context. It is my contention that person knowledge is undervalued.

Liaschenko and Fisher argue that social knowledge connects these three types of knowledge. For example, social knowledge connecting biomedical/scientific knowledge to patient knowledge might be the knowledge a nurse has of a particular surgeon. They may know things about the surgeon such as what types of pain medication they tend to order for their patients, how practiced they are and what techniques they use for a given surgical procedure, etc.

The social knowledge connecting patient knowledge to person knowledge would include things like what the family members say or know about the patient's wishes, information gleaned from other nurses about the patient at shift change, etc. Here is a depiction of her framework of nursing knowledge as she sees it:

Figure 3.2 Nursing Knowledge, Laischenko and Fisher

I want to argue two things about this framework: First, I believe that it has wider applicability than to just nursing knowledge. I believe that it can help us understand

much more than the types of knowledge nurses have. I believe that it applies to physicians, patients, and the general public.

Second, I believe that something goes wrong when one of these types of knowledge is privileged over others. That is, when we have a preference for (as a society, as healthcare consumers and workers) biomedical knowledge, the other two types of knowledge, most importantly, person knowledge, gets pushed aside.

It is my contention that this is what is currently occurring in medicine. There is a heavy reference for the biomedical/scientific knowledge and, when a patient presents with a problem, it is almost automatically that kind of information that members of the healthcare system are after. This kind of knowledge is expensive, and often quite unnecessary. Yet it is what physicians call for before they are willing to make their diagnosis. And it is the nurse's job to prep the patient for whatever procedure they have deemed necessary. Work that goes unnoticed, and knowledge that goes unsaid.

Caring in the Face of Ignorance

Because nurses operate with more than just case knowledge, they are better able to care for patients than physicians in the absence of biomedical/scientific knowledge about the patient than are physicians, who overvalue biomedical/scientific knowledge. Knowledge of the patient and knowledge of the person allow nurses to care for patients when, for example, imaging is not available. Because they take the patient's testimony (with some reasonable reservations) seriously, they are able to care for, say, a broken wrist without an x-ray. They could, for example, treat as if the patient has a broken wrist by advocating for pain medication, splinting the wrist, and giving the patient directions about how to go about getting an x-ray to confirm the

nurse's suspicions that the wrist may be broken. They are able to evaluate the patient with a combination of listening to the patient's story, and asking the patient to perform certain tasks, such as moving their fingers. If a patient's story and their symptomology line up, the nurse can treat without an x-ray.

You would be hard-pressed to find a doctor who was willing to treat a broken wrist as a broken wrist without the diagnostic confirmation via x-ray, or even a CT scan or MRI to look at damage to soft tissue. While doctors may do this when they have no other choice (if the patient does not have insurance to cover the imaging or they are working in another country where imaging technology is few and far between) a physician who has access to these devices is more than likely to use them. Is this in the interest of the patient or in the interest of the physician? Because physicians are paid by the number of tests and procedures they perform, it is hard to imagine that some of the physician's interests don't come in to play. However, we can see, too, that an x-ray confirming a broken wrist could show them more accurately how to treat, say if the bone needed resetting. So it may as well, also, be in the patient's interest. What is paramount, however, is that the patient get prompt care for their condition. In the case at hand, this calls for pain medication and stabilization of the wounded area. These are all things that can be done without biomedical/scientific knowledge. Stabilizing a wrist and ordering pain medication can be done in the face of ignorance of biomedical/scientific knowledge. This is the case because other types of knowledge can be relied on. The patient's ability to wiggle his or her fingers (patient knowledge) and the story they tell about the injury (person knowledge) allow a nurse to care for the patient without imaging. This is critical to

care that needs a prompt response. This is something nurses can do, and some nurses do very well. This is something that physicians, on the other hand, are not so practiced at.

While in our imaginary case of the broken wrist, we are imagining someone with adequate healthcare access, if we change the scenario a bit and allow that they do not have adequate access to health care, the situation, and the need for care in the face of ignorance increases dramatically. Take, for example, my father. He works as a contractor and has had various illnesses and injuries simply as a result of his work. He has no health insurance coverage and, because his care is fragmented, he has little to no health history. When he receives care for something like a broken wrist, he does so at different locations, and pays out of pocket. If my father broke his wrist, it would be very cost-effective for him to work with someone who was able to treat in the face of ignorance. He has had to turn down lab work, x-rays, CT scans, and MRI's all in order to be able to afford his medical treatment.

So who would be an optimal care-giver for him? A nurse or a physician? I argue that a nurse would be better suited to care for someone like my father. They pay attention to his story, assess his symptomology, and can treat him without a lot of imaging or a health record. This is because they listen to him, and listen well. They also pay attention to the way his injury will be impacted by and impact the type of work he does. Even with a severely broken ankle, one of the nurses he saw did not tell him to rest, or even give him crutches. They knew, by listening to him, that this kind of advice and intervention would be ignored, and therefore ineffective. My father does not take time off work for injury or illness. He is up on a ladder with a

broken ankle. This is something only someone who listens will know. They treat him with respect to the reality of who he is, of what his life is like as a person. And this is more effective than having him "follow" orders that are inconsistent with the way he lives his life. Instead, they give him advice on how to continue working with an injury. They treat as if he has a broken bone without an x-ray to confirm. They prescribe pain medication that is effective, but does not impair his ability to work. And above all, they give him comfort and alternative options for follow up care, such as a phone call versus a visit.

Being able to care in the absence of biomedical/scientific knowledge is a skill nurses have developed because they have developed other forms of knowledge that allow for treatment without test results. This is especially important for individuals with limited access to healthcare, such as my father.

Testimonial Injustice

Fricker's testimonial injustice, one of the multiple types of epistemic injustices that she gives voice to in here text, is characterized by when the listener does not grant full authority to the information that they are being given. That is, the information transmitted through testimony actually has a lower level of credibility than information learned another way.

I argue, further, that nurses are subjects of testimonial injustice: where we do not count information gleaned from someone's testimony as knowledge without corroboration—corroboration achieved by bending over backward to verify (or even undermine) that person's claims (Fricker, 2007).

Patient knowledge is knowledge gleaned through the testimony of the patient. Moreover, the nurses then have to testify to the other healthcare workers on behalf of the patient about their pain level, the amount of help they have at home, etc. So nurses get information testimonially and transmit it testimonially. But we have come to undervalue testimony as a proper source of knowledge particularly in a health care setting. We prefer medical charts and lab tests to patient reports of an accident or an illness manifesting in their lives. Physicians also prefer test results to nursing testimony. Why do we suppose this is the case? It is a part of a doctor's job to diagnose and treat, so this handles some of it, but it is also part of their job to care, and without nurse and patient testimony, it is hard to see them playing this role very well.

Collaboration between doctors and nurses is critical to successful patient outcomes. Yet collaboration breaks down when doctors undervalue the testimony of nurses and prefer lab results, etc.. According to Liaschenko, collaboration breaks down when nurses and doctors rely on different knowledge bases. When they share a knowledge base (biomedical/scientific, i.e., case knowledge) collaboration is successful. When they operate with different knowledge bases, e.g. a nurse operating with patient or person knowledge and a doctor operating with simply case knowledge, collaboration breaks down. Physicians dismiss nurses' reports as "vague and confused": when no biomedical cause is evident. They also viewed nurses' evaluation of a patient as "imprecise, and wanted facts, not opinions" (Laischenko, 2007).

Nurses remarked that "doctors have other priorities;" that there was difficulty in getting doctors to order adequate sedation in cases of confusion and agitation in the

ICU; “I can’t get through to them;” “they don’t understand;” “they put you off;” “they only stand at the bedside for fifteen minutes;” “they focus on what they know: hypothetical scenarios” (Laischenko, 2007).

In both the doctors’ and nurses’ remarks we can see that when there is no shared knowledge base, collaboration breaks down. It is only if physicians value and understand patient and person knowledge that they will rectify their assessment of nurses claims. Similarly, if physicians operated with, or at least understood patient and person knowledge, they would not be so quick to dismiss nurse’s reports as “vague and confused.” They need a shared knowledge base to keep collaboration front and center. This is good for patient outcomes, but it is also good for nurses. They will find their knowledge validated and collaboration can continue beyond the biomedical/scientific boundary of knowledge (Laischenko, 2007). So there are two distinct things happening here on the part of physicians. In the first place, they are getting at taking seriously nurses knowledge when it does not stem from the biomedical/scientific. Second, and equally as important, they are taking cues from nurse about how to go about achieving this person knowledge for themselves. That is, their bedside manner is starting to improve as it mimics that of a nurse.

Solving the Problem

Beyond shared knowledge bases, it is also through examination of epistemic imperialism and power imbalances that we can begin to rectify these injustices suffered by nurses and, in so doing, improve our own understanding as patients and members of the general public of the importance of the work that nurses do and the knowledge that they, indeed, have.

Recognizing that nurses do more than what we think they do is essential. Understanding that nurses spend most of their time coordinating care, navigating patients through the healthcare system, passing along information to other healthcare workers, advocating for patients, listening to their stories, and treating in the face of ignorance will highlight this type of work as *recognizable* work.

It will let nurses, other healthcare workers, patients, and the public see the work they actually do as integral, important, and not to be downplayed. It will help nurses advocate for themselves and advocate for patients and families.

Attention to the epistemic problem of privileging biomedical/scientific knowledge over the other types of knowledge nurses have will function to highlight the work nurses do as work. It will help nurses themselves see what they are doing with most of their time *is* work. Once nurses see their work as work, they can disseminate that information to other healthcare workers, patients, and the general public. For, if nurses themselves cannot articulate their work as such, how will the knowledge of nursing work ever be disseminated?

Because testimonial injustice is so deeply ingrained in the way we think about, not just nursing, but deeply infects how we attribute credibility to anyone in a position of creating testimony, eliminating some of the prejudices that have been in many ways absorbed by the practice will undoubtedly prove to be challenging. The answer is not simple naiveté. There are some reasons we don't trust the testimony of others that seem like altogether good reasons. A simple one would be: has this person been honest with you in the past? If the answer is no, it may well be appropriate to look for corroborating evidence to back up their story. Yet if the party in question has

never given you any reason to doubt them, or perhaps you find yourself considering character traits that are quite irrelevant to truth-telling such as class, race, gender, etc. Fricker, as well as myself, would urge that this person be given the benefit of the doubt. We can learn so much from one another if we are willing to take testimony as knowledge. And, as mentioned before, this will never be an absolute avenue to knowledge; there will always be people who use testimony for deception, we stand to lose much more guarding against that unlikely occurrence and by validating the testimony of so many others, we stand to do a lot of good, not just for ourselves, but by legitimizing them as epistemic agents.

Epistemology and Nursing Education

According to Liaschenko, some nurses who were interviewed did not even notice the type of work they were doing, such as helping a patient coordinate referrals, communicating information at shift change, etc. as work (Laischenko and Fischer, 1999) It is difficult to see how others will come to see nursing work as work if nurses themselves don't see it as such. This is why we need to make reforms to the way nursing education is done. All healthcare professionals need to be taught to value their ways of knowing and recognize the work nurses do as such.

I began my inquiry into the way nursing education was being done at a very superficial level—by looking more closely at the mission statements of two leading nursing schools in Minnesota and pulling them apart: the University of Minnesota's school of Nursing and St. Catherine's University.

The University of Minnesota's School of Nursing mission statement is "to generate knowledge and prepare nurse leaders who will create, lead, and participate in

holistic efforts to improve the health of all people within the context of their environments."[2] I was curious about several things: (1) when they speak about generating knowledge, I wanted to know what kind of knowledge they were hoping to generate; (2) when they spoke about holistic efforts, I wanted to know if this meant they took a wider view of what counted as medical care; and (3) when they spoke of the patient within the context of their environments, I wanted to know whether they were referring to person knowledge. Their vision statement was: "the School of Nursing envisions a workplace where nurses lead collaborative efforts to attain optimal health for all people." I was curious about the role of leaders for nurses in collaboration. I sent an email to several people in the nursing department to inquire about their mission and vision statements and received a response.

The University of Minnesota responded to my queries: (1) The School of Nursing has many faculty engaged in research programs that lead to new evidence that informs improvements in practice and more effective health interventions. All the knowledge generated here, through discoveries, is aimed at improving health outcomes. (2) For nurses, holistic means a whole-person approach to care and treatment. Nurses want to understand the person in the context of their environment. If, for example, a patient presents a compound wrist fracture, a nurse's approach would be to investigate bone density, history of skeletal fractures, calcium intake, cause of the fracture, safety in his home, and watch and listen for other signs. Yes, holistic can also mean integrating one type of care with another, such as non-western. (3) I don't know what "person knowledge" is. But nurses (and many of their research projects) focus on environmental factors affecting health. The relevant

[2] http://www.nursing.umn.edu/about/index.htm accessed on: 11/30/2014

context could be something like air quality. Or it could be characteristics of the person's home, such as living with a smoker, or being homeless or not having a fully functioning kitchen, or a patient who is responsible for caring for other family members. All these contextual factors can affect a person's health. In most cases, it's helpful to know the context. In some cases, the nurse may take it upon himself or herself to connect the patient with resources that can help make positive changes to the environment.[3]

At St. Catherine's University, I also found someone to respond to my inquiry. First, it should be noted that St. Kate's mission statement was not accessible to me from the department's webpage. It is an internal document that was sent to me by the director of nursing education.[4] St. Kate's vision statement is: "to be a leading Catholic university educating nurses to lead and influence," while their mission statement is to "educate nursing […] students to become leaders." Moreover, "our commitment to excellence and ethical leadership in nursing is based upon the principles of Catholic social teaching, contemporary nursing knowledge, and professional and academic standards." Additionally, "the department of nursing fosters learning through caring relationships and interdisciplinary collaboration, is committed to the centrality of the liberal arts, and celebrates and reflects diversity in our society."

Their internal document went into some greater detail: For example, they indicate the role of the liberal arts in nursing education stating that it "provide[s] the foundation for and are integrated throughout the nursing curriculum. This liberal arts

[3] Correspondence between Barbara Shafler and myself on: 11/30/2014 and 12/31/2014
[4] Email from Margaret Pharris, Director of Nursing Department. 11/30/2014.

foundation and integration enables students to become critical, creative, and reflective thinkers who embrace a holistic worldview and *seek truth* [emphasis added]." Ethics: "informs application of liberal arts, basic and human sciences, and nursing knowledge. The practice of ethics in nursing professes our respect for the inherent dignity, worth, and uniqueness of each person. Ethics inspires freedom and excellence and champions access." Access: "opens doors to new ways of personal and professional knowing, learning, and leading. Access anticipates the needs of individual students based on their unique goals and plans, resources and experiences, abilities and gifts. Access involves designing processes and systems that maximize each student's success as a learner and identity as a leader. Access promotes lifelong learning." Diversity: "Enhances, expands, and extends the scope and quality of our nursing program. Diversity is integral to and complimentary with our commitment to access. Diversity is a powerful educational resource that enriches the learning environment and inspires excellence." Excellence: "Challenges what is, inspires what could be, and strives to make a difference. Excellence is about cultivating virtue, developing moral character, and living with integrity. Excellence in nursing education demands excellent faculty, excellent curriculum, and excellent resources. Excellence in nursing demands theory-guided, evidence based, reflective practice. Excellence in nursing practice demands competence, collaboration, and caring. Leaders in nursing are exemplars of excellence who exercise leadership in relationships." Relationships: "define who we are and how we act. Teaching and learning take place in relationships. Leadership and followership take place in relationships. Nursing and healing take place in relationships. Relationships need communication and nurtured

environments that invite connection and interaction, reflection and expression, self-awareness and reciprocity. Relationships foster leaders; leaders foster relationships." These documents led to a number of questions for me, so I sent them back to the director of nursing education. She was unable to answer my questions and forwarded them to Kathleen Kalb.[5] I asked her a number of questions including:

1. What do you mean by 'contemporary nursing knowledge?'

   Response: This concept is intentionally broad and refers to the body of nursing knowledge specific to the discipline of nursing as well as the knowledge that is used by nurses to guide nursing practice.

2. With respect to the Liberal Arts section, what truths do you seek?

   Response: The phrase "seek truth" relates to cultivating a spirit of inquiry that seeks truth in both faith and reason. This relates to the University's liberal arts goal, Critical and Creative Inquiry.

3. With respect to the ethics section, Could you explain how you believe ethics informs nursing knowledge?

   Response: I think the intention of this statement is that "Ethics informs the application of nursing knowledge"; for example, how "the practice of ethics in nursing" bears witness to our respect for human dignity in the profession and practice of nursing.

4. What do you mean by personal and professional knowing?

   Response: Personal and professional knowing can be related to the four fundamental patterns of knowing described by Carper (1978) as

[5] Email Correspondence with Kathleen Kalb, 12/5/2014

> empirics, esthetics, ethics, and personal knowing, and more recently, as emancipatory knowing (Chinn & Kramer, 2008; 2011; 2015).

So, what would I change about nursing education? All healthcare professionals need to be made aware of the hierarchy in which they work. They need to be made aware of epistemic imperialism and how it shapes and influences and is shaped and influenced by the hierarchy. They need to learn to work collaboratively and learn to break down the barriers set up by the hierarchy. They need to learn the importance of bedside manner and the importance of hearing a patient's story. They need to pay attention to the way their prescriptions impact that person's life. In order to do that, they need to listen to the patient. They need to take the patient's testimony as knowledge.

Nurses are good at this. Nurses are good at listening to and advocating for patients. All healthcare workers need to learn from nurses who do their job well how they do it. How do they listen? How do they treat without the biomedical/scientific knowledge that doctors privilege? How do they treat in the face of ignorance? And how are they so good at it? How did they learn to be good listeners? What lessons can other healthcare workers learn from good nurses?

Chapter Four: Hermeneutical Injustice, "World"-Traveling, and the Disabled.

In this section, I will offer a revision of Miranda Fricker's notion of hermeneutical injustice—one which has been deeply informed by José Medina's work. In this conception, I agree that there is indeed an epistemic injustice occurring—the inability of an individual or group to make sense of his, her, or their experience—but attend to the concern of *to whom* they are attempting to make sense of these experiences. In line with Medina, I argue that it is possible for an individual to make sense of an experience for him or herself in spite of whether or not these same meanings are acknowledged by others, and, further, that individuals within a marginalized group, too, are able to develop and share meaning amongst themselves without uptake from the dominant whole. Yet hermeneutical injustice occurs when there is no corresponding uptake by the dominant discourse. In this way we could have an alternative interpretation validated somehow, but if the dominant discourse does not acknowledge it, it becomes a minority viewpoint that, for various reasons, is not adopted in the wider discourse. I argue that hermeneutically marginalized groups are indeed bestowed with hermeneutical resources and that, furthermore, in line with the contentions of Medina, they are even possibly better positioned to possess epistemic virtues less accessible to those who are not epistemically and generally oppressed.

Finally, in fleshing out what these obligations look like, or what they amount to, I will turn to the work of María Lugones and argue that it is only through

sustained, often uncomfortable, interpersonal contact with the epistemic other that we can overcome hermeneutical injustice. Moreover, I will attempt to show that *knowing what it is like* is the distinct end product of this contact, which Lugones terms "world traveling," and that, in order to fully appreciate and know what it is like, one has to struggle with and possibly abandon some, perhaps many, of our self-perceived identity traits. Knowing what it is like via world traveling necessitates to at least some degree, altering our own self-conceptions.

To this point, the large majority of the work that I have encountered thus far on "knowing others" and hermeneutical injustice has centered primarily on issues of race, and occasionally gender. I want to turn away from these examples to the less-theorized about group of individuals who identify as disabled. While it is problematic at the outset to speak of such a group existing—the definition that we will adopt later on when we use terms like 'disabled community' and 'individuals who identify as disabled' does not isolate—instead, it squarely locates individuals-in-their-environments, which is where this paper argues that the concept of disability is constructed. So, for our purposes, it will be helpful to make careful reference to a disabled community while keeping in mind that there is no such clearly identifiable group to which our language points that is similarly recognized by the individuals of whom it is constituted. Without a group to make reference to, our ability to say much constructive is undoubtedly limited. Yet acknowledging that there is no singular community to speak of (or with) ought not to stand in the way of our coming to a proper acknowledgement of disability and the need to attend to singular voices in a very particular way.

An ancillary motivation for the choice of this example is the current problematic nature of medical information seeking in disabled communities which clearly connects this problem with the second major undercurrent of my work—the role of biomedical sciences in perpetuating systems of epistemic injustice. This example advances the claim that it is not epistemically helpful in every situation to gather as much information as possible, in this case, about an individual or group of individuals. In fact, it suggests that if you are not sensitive to the role that relationships play in making sense of experience—if you think you understand what you are, but you do not understand who you are relationally or relative to others—then you do not truly understand who or what you are at all. By means of this example, I will elucidate my conception of hermeneutical injustice, maintaining that the disabled community is imbued with unique hermeneutical resources, and that attention to dominant discourse's conceptions of what it is like to be disabled without doing the necessary work of individually combatting hermeneutical injustice by sustained interpersonal interaction with members of the disabled community (a suggestion and recommendation borrowed from Lugones) dramatically limits our understanding. I believe that the completely novel application of Lugones's practice of world traveling is a possible avenue for undoing the epistemic harm done to these communities. And to complicate things further, we need to hold fast to the possibility that, when all is said and done, the community of which we speak may not exist beyond our delineation of it for the purposes of having this and other conversations about it.

Hermeneutical Injustice

In *Epistemic Injustice*, Miranda Fricker details a number of different epistemic behaviors that can lead to the commission of epistemic injustice by one party (or, more often, group) on another. These injustices, in all cases, have consequences that cut both ways. For example, Fricker's discussion of testimonial injustice, reasonably so, focuses heavily on how that injustice impacts the party whose testimony is not taken credibly, and, indeed, the negative implications for someone who finds themselves not taken as a credible source are undoubtedly great. The potential negative implications to the individual who commits such an act of epistemic injustice (that is, the person who denies the testimony of another) is only rarely, if ever, alluded to by Fricker. I am interested in the influence of the perpetration of epistemic injustice that cuts both ways. While the most obvious example of a harm done to the perpetrator of injustice is ignorance, it is not at all clear that ignorance necessarily amounts to a negative influence—take Mill's white ignorance for example. Simple ignorance could really be seen as a benefit to the perpetrator of epistemic (and ordinary) harm. So instead of exclusive attention to the ignorance that results from one individual's commission of epistemic harm, I would like to attend to the whole spectrum of harms to which they are subjecting themselves. Not taking someone's testimony, for example, leaves them without information obtainable by someone who is willing to value the testimony of another and without that individual's particular take on what he or she is testifying to.

While I do explore the epistemic harm done to the perpetrator, which Fricker does not spend much time with, I in no way mean to diminish or mitigate harm to the sufferer. I think both sets of epistemic harms are worthy of examination, and, in

investigating them side-by-side, we might have a privileged perspective from which to identify what the epistemic goods are that are being infringed upon in instances of hermeneutical injustice (which, for Fricker, has no one perpetrator), especially when the harms tend to cut both ways.

To begin with, however, it first needs to be established what exactly is meant by hermeneutical injustice. Hermeneutical injustice occurs when one group's collective social understanding prevents a second (non-dominant) group from forming their own understanding, and (if we allow that they do somehow form an understanding) preventing that understanding from being widely shared. Fricker writes,

> one way of taking the epistemological suggestion that social power has an unfair impact on collective forms of social understanding is to think of our shared understandings as reflecting the perspectives of different social groups, and to entertain the idea that relations of unequal power can skew shared hermeneutical resources so that the powerful tend to have appropriate understandings of their experiences ready to draw on as they make sense of their social experiences, whereas the powerless are more likely to find themselves having some social experiences through a glass darkly, with at best ill-fitting meanings to draw on in their effort to render them intelligible. (148)

We are all the generators of social meaning then, when we turn and use that meaning to make sense of our own experience, it should all check out—as this is what we designed it to do. Although we indeed generate social meaning, it is not the case that said social meaning is readily put to use by us and may instead be imposed on us by someone in a position of significant social power.

Because those of us in positions of social power are the generators of social meaning, then, according to Fricker, when we turn and use that meaning to make sense of our own experience, it all checks out. On the other hand, when those of us

who are not in positions of social power use those same meanings to make sense of our own (presumably divergent) experiences, we misinterpret and distort what we can in order to find fit, and do away with the rest.

Some work needs to be done with respect to what Fricker means when she speaks of "making sense of one's own experience." Medina problematizes this description of Fricker's. Because Fricker couches hermeneutical injustice in terms of semantics, she does not adequately take the time to consider the question of *to whom* one is trying to make meaning. It would seem to be the case that on Fricker's account, it is the individual him or herself who is not able to find meaning. Yet hermeneutical injustice only occurs in a relational context. There are numerous players at stake. Of course, there is the individual—but there is also the group with whom their experience may resonate, the dominant group, and finally, the greater collection of these subgroups—the group intended to speak for us on the whole: this is the group that institutes and maintains the dominant discourse—where we get our social meaning. Yet we can see how meaning has to, in some sense, work its way up the hierarchy: first, with individuals making meaning for themselves, then to others like them, then to others who may not be so receptive, and ultimately, it can become part of dominant discourse, and our meaning can be and is understood by all. Notice that the dominant discourse is something that even members of marginalized groups are exposed to and likely understand, as they often (and which will be discussed more fully shortly) develop a double consciousness which allows them to harbor both their own self-conceptions and the dominant discourse's conception of themselves simultaneously.

Fricker, however, uses examples like that of Carmita Wood, a woman who, for a long time, had been suffering from work-place sexual harassment but (according to Fricker) because there was no recognition of sexual harassment in the dominant discourse, did not have appropriate understandings of her experiences (149). Fricker writes, "The cognitive disablement prevents her from understanding a significant patch of her own experience: that is, a patch of experience which it is strongly in her interest to understand, for without that understanding she is left deeply troubled, confused, and isolated […] Her hermeneutical disadvantage renders her unable to make sense of her ongoing mistreatment" (151).

Fricker is making two extremely strong claims in this passage: first, that Wood *does not actually understand* an aspect of her own experience; and second, that this is not just any aspect, like something accidental or trivial, but an aspect "of experience which it is strongly in her interest to understand" (151). No amount of exposure to sexual misconduct in the workplace without collective corroboration would warrant Wood's understanding her own experience. Fricker is not claiming that events such as speak-outs would help Wood process her *preexisting understanding* in a way that is more in line with dominant social meaning. Thus, Fricker is not saying that Wood, after consciousness raising about sexual harassment, has new information about, is aware of, is less susceptible to, or understands *better*, her experiences; she is saying that Wood now understands what she didn't before.

This overreaching on the part of Fricker to make the case for hermeneutical injustice has not gone unnoticed by her critics. In Rebecca Mason's "Two Kinds of Unknowing," she argues that Fricker's use of the example of consciousness raising

about sexual harassment fails to demonstrate that there was a lack of prior knowledge. On Mason's account, it is not the case that women could not understand their experiences of sexual harassment before it was named. They knew that something was wrong, organized around it, and gave it a name. For Mason, there was this thing that they were experiencing before, that they *knew* they were experiencing before, and to it they gave a name. Medina argues in a similar vein that Fricker places too much emphasis on the linguistic accomplishment of naming the phenomenon, as though it were somehow in this act of naming that an experience achieves meaning.

The criticism of Fricker on this point by Mason, Medina, myself, and others, does not render hermeneutical injustice flat-footed, however. Something much more subtle had to transpire for naming, identifying, and appropriately giving meaning to such happenings. Before these women came together to share their experiences, they likely had the sense that something was wrong, but were at a loss for a way to articulate it. Or worse still, each of them thought it was simply something to be taken in stride. In either case, though, there was a something of which they were aware. There was a knowing without a name. Coming together and finding other voices that validated how uncomfortable they felt when these actions were performed toward them gave them the power they needed to name the phenomenon, and begin (however small) an uprising to push against its unchecked happening against women in the workplace. Mason writes, "affirming that women—prior to naming sexual harassment—were able to understand their experiences of it suggests an alternative kind of unknowing that is at work when hermeneutical resources fail to countenance the experiences of some members of society" (298).

In sum, then, as long as Fricker allows for the type of meaning making as described above by the non-dominant group, the blooms through the cracks in the sidewalk, I think that her theory has accurately identified the key players at work here in this chapter which will need to be made use of by both the dominant and non-dominant group. With this picture in mind, then, I take hermeneutical injustice to refer to the dominant group's ability and inclination to overlook the meaning already in place by non-dominant groups and, in so doing, retarding the spread of that meaning both across these two groups and amongst members of the non-dominant group themselves. This is consistent with Medina's desire to identify the "to whom" the making sense of an experience is being done. For Medina, and for me, then, hermeneutical injustice is a failure of communicative and interpretive responsiveness. For this reason, meaning is not taken up by others.

With an operational definition of hermeneutical injustice in hand, then, it would be prudent to turn to the epistemic consequences of such a harm. On Fricker's account, the primary harm done is to the marginalized. Recall, on Fricker's account, because we all participate in the dominant discourse and achieve understanding of our own experiences via relation to it, subjects of hermeneutical injustice find themselves lacking the resources they require to give legitimate voice to their own meaning. This is an extreme consequence, and one that we have previously butted heads with. But even if we disallow this as a necessary outcome of hermeneutical injustice, there are still epistemic consequences for those who are not heard. Clearly, not being able or allowed to adequately give voice to your own experience has the potential to undermine your sense of epistemic agency. Why is it that nobody is listening? Why is

it that you are not being understood? It is easy to see how one might begin to answer those questions by attending to features of themselves, not necessarily seeing the consequences as a product of their environment. There is something epistemically questionable about *me*, about *my* experience, about what I am trying to convey and how I am trying to convey it. I am not a proper epistemic agent—a generator of reliable, intelligible, information.

This would be a case of epistemic insecurity. However, victims of hermeneutical injustice, in some cases, are not pushed so far. In fact, Medina argues for a host of epistemic virtues that are more easily accessible to the oppressed (although clearly not universally taken up). In this case, a victim of hermeneutical injustice who is not pushed to such an extreme is better positioned to have the virtue of epistemic humility. While someone with the virtue of epistemic humility when confronted with hermeneutical injustice is likely to posit the same questions: 'Why is it that nobody is listening?,' 'Why is it that I am not being understood?,' they are not necessarily going to jump to the conclusion that they are not legitimate epistemic agents. An individual with the virtue of epistemic humility does not necessarily see their claims to be authoritative—and in recognizing that *this* is possible, they are less likely to conclude that the claims and positions of others are necessarily wrongheaded. This, of course, is only one possibility of epistemic humility—the other would be extreme epistemic submissiveness, where one simply backs down to the epistemic authority of another.

In this way, a victim of hermeneutical injustice likewise has the potential to be more open-minded regarding the possibilities of what can be said to be epistemically

authoritative. It has long been argued in feminist and critical race theory that victims of oppression have "dual consciousness." That is, they have the ability to see themselves through their own eyes, as well as through the eyes of their oppressor. Medina writes, "Although oppressed subjects can indeed fall victim to socially generated illusions, they often have more resources to undo these illusions, they have a richer (or more heterogeneous) experiential life that they can use to dismantle the accepted description of reality and rules of the day" (46). While Medina is quick to give voice to at least this benefit of epistemic humility, there are other benefits worth noting. For example, those who are epistemically humble are much better at seeing through the illusions of privilege as positions of privilege are generally locked in by an unwillingness to see things any other way than that which suits them whereas an epistemically humble individual is practiced at entertaining perspectives which might render the privileged less comfortably situated.

This ability to navigate amongst multiple social cognitive constructions puts the oppressed at something of an epistemic advantage. They have the dominant cognitive construct very much forced upon them, yet are able to better understand themselves both as participants in dominant discourse (exposing them to how they are perceived by the oppressor) and as individuals, however unfortunately, outside of the dominant discourse (hermeneutically oppressed). Fricker's rendering of hermeneutical injustice does not as readily allow for this dual or multiple consciousness. I regard this fact as something of a drawback of her account.

Recall that, for Fricker, whenever we encounter a hermeneutical gap, an experience must be rendered unintelligible for everybody. In contrast, on Medina's

reading, this is not necessarily the case. When the dominant interpretation fails to recognize and interpret an experience, seemingly divergent individuals—individuals whose experiences are being overlooked or individuals who are being made aware of this failure of recognition—can begin to engage in what he calls "hermeneutical resistance" (100). In contrast to Fricker's contention, he writes, "public silences, even when they do involve unfair hermeneutical disadvantages should not be equated with complete expressive and interpretive incapacity" (101).

What it is like to be disabled

The collective social understanding does not simply belong to the dominant group. Attention to how the collective social understanding operates across the dominant/non-dominant divide, even if it is borne out of the attitudes of the dominant group, as in the case of white ignorance, we create meaning that can be utilized by both groups all the same. In considering how dominant discourse views disabled individuals we'll start by developing a conception of what it means to be disabled borrowed from the dominant discourse. Once this is in place, we will be in a position to challenge it with the work of disabled theorists themselves.

This example poses a particularly poignant challenge to my work for two reasons: first, the practice of medicine is a leading contributor to the hermeneutical injustice suffered by this community and, because attempts were made to understand rather than ignore (though the average person tends to do more of the latter), the malicious or at least innocuous intentions inherent in most other cases of hermeneutical injustice are not as obvious a factor. If damage is done by someone

seeking knowledge responsibly versus underhandedly, epistemic harm still may have occurred and, as such, investigation of both varieties stand to inform and enlighten our inquiry. In this case, because (at least some of) the intentions of the medical community were beneficent, my inclination to explore the epistemic harm to the perpetrator seems less inappropriate than it often does elsewhere, even if Fricker protests such an analysis. The second and final reason this example poses a special challenge is that the traditional roads tread for breaking down incommensurability between two groups and their respective understandings have not been extensively tested here—that is, there has not been nearly as much theorizing about how able-bodied individuals can or should come to know what it is like to be disabled—and, for this reason, novel information will be gleaned from the application of this understanding regarding whether or not it turns out to be viable resources for doing so.

Before we can talk about fixing the problem of hermeneutical injustice suffered by the disabled, however, we first need to set out what the problem is. We have thus far spent a good deal of time on the problem of hermeneutical injustice in general, but we have yet to move to the particularities of this case. I want to start by laying out some knowledge claims *about* the disabled. Much of this, as mentioned previously, originates with medicine, but our ultimate aim is to identify key elements of our social understanding of disability. From this, we can identify any inaccuracies, lapses, or pervasive misconceptions that are not present in our brief review of accounts from disability theory itself. Even if we unearth a mismatch—we have not yet demonstrated that we have isolated a case of hermeneutical injustice. To do so, we

must push further to determine whether it is the dominant social construction of disability that is keeping an understanding of disability stemming from disability theory itself at bay (which I believe it has and is). After establishing this instance of hermeneutical injustice, we will turn to the work of Maria Lugones, Ofelia Schutte, Jose Medina, and others as a means of identifying the epistemic goods recoverable from disrupting this particular instance of hermeneutical injustice.

> Any restriction on or lack (resulting from an impairment) of ability to perform an activity in a manner or within the range considered normal for a human being. World Health Organization (WHO) definition of 'disability'

In a review of recent scholarship in feminist disability studies, Thompson (2005) briefly delineates five narratives of disability (11). The first of these she deems the "biomedical narrative." This is probably the depiction of disability we are most familiar with. The biomedical narrative demonstrates disability as the malfunctioning or malformation of the human body, due to some disease or defect. Physicians are esteemed as experts and are heralded as "cognitive authorities," even outside of their practice (117). You would presume that there is good reason, then, to follow their lead—especially when we are speaking of disability with an understanding that it is a medical condition. (We will return shortly, however, to the dangers of unchecked reliance on physicians and medical information/ways of knowing.)

There are a number of implications stemming from this view of disability. First, there is the tendency to generalize disabilities for the purpose of treatment (Wendell 71). While a doctor might be treating two different patients, both of whom suffer from Multiple Sclerosis, the extent to which these two patients may or may not be disabled can vary widely. As such, a doctor may not be inclined to refer to a

patient's diagnosis and then qualify it with the expression of symptoms *x*, *y*, and *z*, and further specify the degree to which the patient is suffering from each of these maladies. We must hope that this is, at the very least, characteristic of the physician's personal notes on each patient, but we can see why classing patients simply by diagnosis is an obvious starting point, particularly if we consider this as a function of physicians acting as medical researchers. Unfortunately, this behavior on the part of doctors has bled into the general public's use of terminology surrounding what may be a diagnosis for a very specific condition as something of a catch-all term.

A second consequence of the biomedical view of disability is the notion that medicine is meant to control or treat our disabilities (and subsequently, that disabilities are meant to be controlled). Susan Wendell writes, "Scientific medicine participates in and fosters the myth of control by focusing overwhelmingly on cures and lifesaving medical interventions" yet, in the same paragraph, she iterates that physicians *do not* demonstrate modesty in either their own knowledge or in their field's ability to produce desired results even in response to their failures (94). This is, of course, troubling on two fronts. First, it presumes that something is wrong that is in desperate need of fixing. There is a paradigm into which human bodies should fit, and when they do not fit that paradigm, it is the body that needs to be "fixed" rather than the paradigm. And given our advanced medical technology, there is a great deal of "fixing" we are able to do: cochlear implants; surgical "stretching" of limbs (this amounts to literally severing, spacing, and resetting bones repeatedly); prosthetics; anything we can do to make an aberrant body or condition more representative of the paradigm. This fosters the attitude that the human form is something we can and

should have close control over—and we should utilize that control for "improvements." Second, as Wendell mentions, even in the face of their own failure, physicians are reluctant to give up this illusion and aspiration of control. If a particular method of treatment is unsuccessful, it is not the case that physicians are inclined to throw in the towel. Rather, they may make repeated attempts at the same treatment measures, or explore a plethora of potential remedies with the undergirding impulse that something, anything, can and should be done.

This draws out the distinction between two foundational principles with which health care professionals are intended to operate in biomedical ethics. The principles of non-maleficence and beneficence. While more often than not functioning in unison with one another and endorsing the same actions, the principle of non-maleficence constitutes the vow with which the Hippocratic Oath opens: first, do no harm. In cases such as those described above, where the desire to help—the inclination toward beneficence—begins to overshadow a physician's duty of non-maleficence, a doctor may in fact be causing harm in their seemingly innocuous attempt to help. In the pursuit of control and remedy mainly, we can assume, motivated by beneficence (although the desire to push medical boundaries and practice investigatory medicine may, too, be in play) the primary duty of non-maleficence can take an unintentional backseat.

One cannot ignore at this juncture the ability of medical technology to detect certain disabilities in utero: for example, hydrocephaly or trisomy 13. With the advancement in the prenatal detection of anomalies, we have had corresponding improvements in our ability to "fix" certain conditions by means of prenatal surgery

as well as increases in incidences of genetic abortion. In fact, two conditions that have been "targeted for extinction" include spina bifida and Down syndrome by our increased ability to detect them prenatally and early enough to abort if the woman or family chooses to do so.

This language of being "targeted for extinction" is undeniably startling, and one can imagine what impact hearing this fact might have on an individual suffering from either of these conditions. What is not meant by this language and corresponding initiative is to do harm to existing individuals with these conditions (yet ancillary harm is indeed done in that resources (both financial and with respect to medical research) that may have been directed at improving their living conditions are becoming increasingly scarce, and, with fewer individuals being born afflicted with the condition, even fewer resources will be allocated to this cause in the future). Instead, prenatal genetic testing is being used to detect developing fetuses with these conditions at which point women are given the option of having a genetic abortion performed. At this juncture, this choice remains the woman's, yet nearly 75% of women who learn that they are carrying a baby with Down syndrome elect to abort. With such a high rate of termination, and given the fact that Down syndrome is a spectrum disorder (that is, although it can be prenatally detected, it cannot be prenatally determined how severely the child will be affected by the condition, and many individuals with Down syndrome go on to live fulfilling, independent lives) one might question the nature of the freedom with which this "choice" is exercised.

Similarly, individuals with spina bifida (a congenital condition resulting from the improper fusing of the neural tube and spinal column in the early weeks of

pregnancy) live lives that are colored very differently by their condition. While spina bifida is an undeniably painful and dangerous condition—making the individual prone to disease and infection and generally requiring multiple surgeries, beginning in infancy—notable individuals suffering from this condition, such as Alison Davis go on to live productive and, to them, satisfactory lives (285). Davis was born with spina bifida in an era when there were no prenatal tests to detect this condition. Her physicians told her parents that her quality of life would be very poor, and that it would be in everyone's best interest not to treat her condition (and presumably allow her to die from complications such as infection). Her parents did not take the advice of her physicians, and Davis was subjected to innumerable surgical operations throughout her life beginning shortly after birth, and was still left paralyzed and incontinent. Yet Davis composed an article in defense of children born with similar conditions against having their quality of life predicted for them by physicians immediately after birth. Although she was physically affected by her condition, Davis went on to achieve advanced degrees and participate in what she takes to be a life worthy of living. She argues that the doctors misinformed her parents about her potential quality of life and warns that such a thing cannot necessarily be predicted so early in life for conditions such as hers.

> In our increasingly technologically focused and highly specialized healthcare arena, there continues to be a systemic concern that subjective experience is unscientific and thus unreliable in knowledge creation in medicine, particularly when it conflicts with expert opinions. Those who report a much higher quality of life than projected by experts are often discredited as mistaken or holding lower expectations due to their impairments. (Anita Ho, 114)

While it is the case that, for certain conditions, such as Tay-Sachs, a short, miserable quality of life *can* be accurately predicted, and this is a condition that parents can be screened for being carriers of prior to even conceiving a child together (as it is a recessive disease and both individuals must be carriers in order for the condition to manifest), for others, including the two previously mentioned which are being "targeted for extinction," quality of life, particularly quality of life from the perspective of the child *cannot* be predicted with great accuracy. So physicians are making recommendations to prospective parents based on definite information that their child will suffer from an impairment, but only probabilistic information, if that, regarding the child's potential quality of life. And when doctors are viewed as authority figures by these prospective parents, the decision to terminate a pregnancy may be heavily influenced by that doctor, and the medical community's, *opinion* of the potential quality of life for an individual born with either of these two conditions. Given that these are conditions that are indeed "targeted for extinction," it is not difficult to suppose that these opinions are overtly negative ones.

> […] numerous studies show that health care professionals continue to hold negative attitudes and assumptions toward impairments and the quality of life of people living with these impairments. Reported negative attitudes raise questions of whether these patients can take professionals' proclaimed good will for granted. The medical model for disability, which continues to be the paradigm among many clinicians, pathologizes experiences of patients with impairments and neglects how social barriers and professional attitudes have the potential to affect quality of life.
> Anita Ho, 113

The final implication of the biomedical narrative of disability is that disabled individuals themselves can be influenced by these perceptions. In describing

symptoms to their physician, for instance, they may lapse into terminology characteristic of their condition generally rather than trying to give an accurate, subjective account of their experience. If patients are unable to communicate effectively to their doctors, they may well not get the individualized treatment they need for their condition as it affects them specifically; they may be prevented from receiving the equipment and accommodations they need to lead their life with as little hindrance as possible (Wendell, 133). But, because they may be operating from the concern that, if the manifestation as they describe it is not generically descriptive of their condition, they may get no diagnosis or treatment at all, they may be more inclined to "stick to the script," as it were. Anita Ho warns that "[w]hen professionals and patients identify different symptoms as salient and have divergent interpretations of various experiences, in determining appropriate care plans professionals' interpretation and assessment of them even often trump the patient's own situated experience based on the presumed credibility gap" (114).

The second narrative pointed to by Garland-Thompson (2005) is the sentimental narrative. On this view, persons with disabilities are seen as "occasions for narcissistic pity or lessons in suffering for those who imagine themselves as non-disabled" (11). The sentimental narrative, whether overtly or covertly, has probably occurred to you, even if only as a child. Consider the scenario of being stopped at a red light in your car. As the light begins to change from red to green, you watch in pity as a young man with cerebral palsy struggles to cross the intersection on crutches. (And why not: imagine it is a slushy February day in Minnesota.) What emotions does this scenario elicit for you? For me, I am inclined to feel sorry for this

young man. I pity his condition, his plight. I wish that I could help knowing full well that I am not positioned to do so (behind the wheel of my car), nor would I be likely too, even if I were better positioned to help, such as if I were crossing the street on foot in tandem. There is something that makes us feel uncomfortable about offering assistance to the disabled and, I believe, it is in part a product of the sentimental narrative of disability. In offering help to someone with a disability we would be reinforcing our own conception of that person as someone who is necessarily dependent on others. Offering help in accomplishing an ordinary task could be an occasion for shame for that individual. Feeling sorry for someone who is disabled inhibits our inclination to help because helping reveals that we feel sorry for them in the first place. Many of us who are able-bodied find it difficult enough to accept help (or charity, or pity) from others—even if we need it but it is the case that being offered help or charity makes us acutely aware of our potential shortcomings, and this can incur feelings of shame even when there is nothing "wrong." In returning to the case of disability, Wendell echoes, "Disabilities tend to be associated with tragic loss, weakness, passivity, dependency, helplessness, shame, and global incompetence" (63).

The third narrative identified by Garland-Thompson (2005) is one in which disability is something that is meant to be overcome. This view necessarily renders disability a personal defect that must be compensated for to get along in the environment. While a positive note rings through this narrative (even though it still suggests that disabilities are "problems" in need of "fixing"), its sound is deadened by the ominous note of its companion: on the view that disabilities are something we are

meant to overcome, we must too be imbued with the resources to carry out that aim. While providing resources for individuals to overcome their disabilities might not at first sound so onerous, it begins to if you consider some of the attitudes that are commonly linked to providing said resources.

In a quite different sense of disability, according to Linton (1998), it is common to view the disabled is as a drain on precious societal resources such as healthcare, education, and housing. The way in which spina bifida and Down syndrome are being "targeted for extinction" is both a product of this view and, as mentioned previously, is having and will have a significant impact on the resources being allocated to treat individuals with these conditions. While it might not seem so nasty at the outset to suggest that a disability is something that should be overcome, even with its inherent undertone of a disability thereby being an undesirable personal defect, the suggestion that money spent on helping individuals overcome their disabilities is done so unwisely and inappropriately surely highlights the way in which the narrative of overcoming has inherently negative underpinnings.

The fourth is the narrative of catastrophe (Thompson 2005). On this picture, disability is something so overwhelming that it either brings about courage (and possibly shifts you into the former narrative) or causes a devastating physical and emotional defeat (and perhaps instead lands us back in the sentimental narrative). Either result of the playing out of this narrative steers us away from the potential view that disability is something that is not a cause for crisis—that disability can merely render someone in need of adaptive strategies to lead an otherwise ordinary life.

The narrative of catastrophe from the perspective of an able-bodied individual is, in my opinion, easily established, although this does not make it necessarily correct or somehow more defensible. Consider, for example, giving birth to a child with an unanticipated disability. While all of your life-planning may have centered on the overwhelming disruption of bringing an infant into your world, it was surely not centered around having a wheelchair accessible nursery or "baby-proofing" your home for an child that perhaps can't literally even see to avoid the hazards of wall-sockets. Although I have never experienced what this would be like as a parent, I can imagine that one might feel completely devastated and out of control—that one would view this event as catastrophic. I can also imagine a parent who, perhaps instantly (although I cannot see myself reacting in this way), responds with great strength and an emboldened motivation for immediately and dramatically altering her own life, and preparing to alter the life that she may have had planned for her child to compensate as best as possible for this unexpected modification.

I can also imagine the narrative of catastrophe falling out of the experience of an able-bodied individual becoming disabled. For example, in the case of Donald (Dax) Cowart, this, average, healthy young man in his twenties was subjected to second and third degree burns covering the majority of his body after an accidental explosion (69). Initially so overcome with the pain, Dax requested that his treatment be stopped and he be allowed to die. When his request was repeatedly denied, Dax began to realize the condition in which he would live the rest of his life: completely blind, without sensation over much of his body, without fingers, and without the normal function of his arms and wrists. Dax's reaction was to sink into a deep

depression, characterized by suicidal thoughts. He went from being a young man poised for a career in the Air Force to seeing himself as capable of doing no more than "selling pencils on the street corner." Dax's response to his disability was in-line with the catastrophe narrative—and his resultant attitude was one of defeat and desperation.

Ultimately, Dax completed law school, passed the bar exam, and became an extremely successful attorney, even given his physical limitations. Yet he still maintains that, although their "hearts were in the right place," Dax's physicians were wrong to deny him his request to discontinue treatment. His argument hinges on the contention that, no matter a patient's condition—if they are deemed psychologically competent (which he was, by two separate psychiatrists) their medical decisions should be honored and, despite his ultimate success, he should have been allowed to die). So, in Dax's case, we see the manifestation of the narrative of catastrophe and, ultimately, the winning out of the reaction of "desperation," yet the occurrence of courage in Dax's achievement of a life beyond what he imagined possible for himself. In this way we see the narrative of catastrophe challenged by Dax's case.

The final narrative (Thompson, 2005) identifies disability as something that we can and should avoid at all costs. The term, 'abjection' means to discard or cast out. This reading of the fifth narrative is consistent with one of the most pervasive practices regarding the disabled both across history and time. According to Linton (1998), the view of the disabled person as "the pariah" is common to nearly every culture, and practices surrounding this view even occur contemporarily (38). Viewing

disabled individuals in this light has led to countless horrific acts including their isolation, abuse, and even murder.

Historically, in western culture, people with disabilities have been institutionalized. While the conditions of these institutions progressively improved with time, the attitude that people with disabilities should be "managed" and kept out of the general public was pervasive all the way through the mid-twentieth century. Currently, the institutionalization of persons with disabilities is less common, and families are encouraged to live with and care for disabled family members, and in most cases with financial and medical assistance. Yet abuse of the disabled, even by family members, still occurs—and at higher rates than we might anticipate or want to admit. Finally, although it is no longer/not a part of western culture to murder disabled individuals, we have already explored contemporary attitudes toward genetic abortion. Even amongst those with convictions which we'd ordinarily expect to be most staunchly opposed to the termination of life—natural law theorists—by way of the principle of double effect, room has been made in the most severe cases of suffering, to allow for merciful termination of life.

Through the fleshing out of these five narratives, we have achieved a brief glimpse into the dominant-group's social understanding of disability, or what it is like, what it means to be disabled. According to how the dominant discourse is meant to operate, this is the understanding of what it means to be disabled that "works" if we ever do become disabled, or have close encounters with individuals who are, for this is to be the correct social understanding. In laying out these narratives, I have explored the way in which they more or less ring true even for me when approached

uncritically and yet we are still faced with the question of whether or not we've gotten it right. That is, do these narratives capture the social understanding of disability that we would find in the non-dominant group?

The short answer is no. Each of these five narratives of disability are currently being debunked by work in disability studies. Let's take a closer look at a few of these cases: To begin with, there has been significant push back on a biomedical conception of disability. This has been the prevailing understanding of disability for centuries but fails to properly situate disability, as it locates disability squarely in the individual. At the very least, disability needs to be seen as the interaction of societal, social, and individual factors. It might seem reasonable to conclude that being 4'1'' is a disability. But if it turns out that cars and houses are built for people who are less than five feet tall, and that the average height of a full-grown man is only 4'8'', you would probably think twice. This kind of thinking relocates disability and places it in a wider (albeit still spatial) context.

Garland-Thomson argues for an alteration in the very language we use when speaking of disability to fully drive this point home. She argues that the "traditional understandings of disability as lack, excess, or flaw *in bodies*" [emphasis added] gets it wrong (591). This understanding is a product of the biomedical narrative of disability. She argues for an understanding of the relationship between a biological impairment and disability to mirror the relationship developed by feminist theorists in separating out the difference between sex and gender (591). The term 'sex' refers to the biological status of our bodies. That is, whether we have male or female reproductive and secondary sex-linked biological structures. If an individual has a

vagina, uterus, ovaries, fallopian tubes, mammary glands, a female pelvis, or some combination thereof, then they are biologically sexed 'female.' Yet there is no necessarily causal link between being biologically sexed female and being of the female gender. That is because being gendered female is a social construct. It says something about part of our social identity, not necessarily something about our biological sex. Being gendered female is a social construct, and it is an identity. Society has created gendered roles and individuals participate in them in any number of ways; but it is not the case that simply because one's sex is female, their gender is correspondingly so.

In the same way, we should understand the term 'impairment' to refer to some biological fact about our bodies. This term might refer to damaged occipital lobes, a severed or obstructed spinal cord, a degenerative disease, the presence of an extra or absence of a standard chromosome, or a physical stature above or below three or more standard deviations of the norm. An individual could have any one of these biological characteristics, a combination thereof, or one or more of thousands of potential others. Having such a feature would make you biologically impaired. However, it is not the case that having a biological impairment constitutes having a disability, in the same way that being biologically sexed female does not mean you are of the female gender. For Garland-Thompson, being disabled is a social construct and a social identity. It is a fact about how our biological impairments do or do not render us "unfit" for our environment. For example, having damaged cochlear structures is a biological impairment. This biological impairment may render someone unable to hear. In a society where there is no relevant audible information,

this person is not disabled. In a society where there is, this person is considered disabled because a biological impairment renders them improperly "fit" for their environment. To be unable to hear is to be deaf. To be deaf is a feature of your social identity. In a hearing community, it renders you disabled. In the Deaf Community, it does not. Disabilities are therefore social constructs. They are the coming together of a biological impairment and a societal fact and if there is a "misfit," that is, if the biological impairment renders that individual unable to operate in some common and relevant way in society, then that person is disabled—and being disabled is a feature of their social identity.

As I mentioned previously, Garland-Thompson urges us to adopt this language of 'misfits' or 'misfitting' in lieu of 'disabled.' This language has imbedded in it a necessarily relational connotation. It does not make sense to talk about something fitting or misfitting if there is nothing that we are worried about fitting it into. Adopting the term 'misfit' for people who socially identify as disabled requires that we consider this relational aspect. It requires that we take in to account the context in which we consider people with disabilities, rather than just viewing disability as some physical or biological fact about *them*—abstracted or abstractable from their location. One distinctively helpful feature of this position is that, "the utility of the concept of misfit is that it lodges injustice and discrimination in the materiality of the world more than in societal attitudes or representational practices, even while it recognizes their mutually constituting entanglement" (593).

I think that this is absolutely right. It is right to recognize disability as a social construct and as a feature of social identity. The use of the term misfit enforces this

fact and, moreover, it places special emphasis on features of the material world and how those features might constitute or contribute to this identity. While emphasizing the material world, we deemphasize the role of the body in isolation, yet we do not lose sight of the fact that the material world is a product of societal attitudes and vice versa. So even though discrimination against people with disabilities is very much imbedded in the material world, it is still a feature of our social attitudes because our social attitudes construct the material world and the material world influences our social attitudes.

We may have made it the case that a building is not wheelchair accessible; yet we don't get any discriminatory sense from this until we see how this feature of the building prohibits certain others from entering. When we see how these prohibitions limit individuals from participating we start to see discrimination, and we may start to validate this discrimination (we should not have to accommodate) or we may begin to dismantle it (wheelchair accommodation is necessary). Being disabled is a social identity that says something about the way you fit or do not fit in the world that society has constructed, the world is constructed by society discriminatorily, and the way in which society reacts to seeing how the world discriminates can begin to feed or dismantle this discrimination.

Tobin Siebers urges us in this same direction and writes, "Disability is not a physical or mental defect but a cultural and minority identity. To call disability an identity is to recognize that it is not a biological or natural property but an elastic social category both subject to social control and effecting social change" (4). So, in the very same way that my participating in the social category of 'woman,' works to

delineate the minority group associated with the name, disability ought to be similarly seen as what makes us "others.").

> 'Otherness' is maintained by culture but also limits culture profoundly. Canadian and United States culture rarely include people with disabilities in their depictions of ordinary daily life, and they exclude struggles, thoughts, and feelings from any shared cultural understanding of human experience. This tends to make people with disabilities feel invisible (except when they are made hypervisible in their symbolic roles as heroes or tragic victims), and it deprives the non-disabled of the knowledge and perspectives that people with disabilities could contribute to culture, including how to live well with mental limitations and suffering. Because disabled people's experience is not integrated into the culture, most newly disabled people know little or nothing about how to live with a long-term or life-threatening illness, how to communicate with doctors and nurses and medical bureaucrats about their problems, how to live with limitation, uncertainty, pain, and other symptoms when doctors cannot make them go away. Nor do they have any idea that they may gain something from their experiences of disability. There is a cultural gulf between the disabled and the non-disabled; to become disabled is to enter a different world. Yet experiences of living with a disability are not by their nature private, separable from the rest of life and separable from the rest of society. They can and should be shared throughout the culture as much as we share experiences of love, work, and family life. (Wendell 65-66)

From a handful of the contemporary forerunners of disability studies, then, we get a social understanding that is distinctly different than the understanding gleaned from the narratives present in the dominant-group. Moreover, in both Sieben and Wendell it is suggested that the operation of the dominant group's social understanding is interfering with a proper social conception of disability. For both Sieben and Garland-Thompson, we need to move past the biophysical and into the

social, and for Wendell, we need to recognize the role of culture in obscuring the plain facts of disability. In both cases, we see evidence of hermeneutical injustice. The dominant social understanding of disability allows no room for the non-dominant. The non-dominant social understanding is *there*, but it is not receiving the proper attention or the necessary resources to have its convictions laid plain to epistemic others.

Cultivating hermeneutical justice

Given that there is meaning available to us from the perspective of the disabled, we need to go about articulating a way in which this meaning can be respectfully accessed. Attention to the dominant narratives of disability are giving us, at best, an inaccurate picture of what it is like to be disabled and, at worst, a discriminatory and harmful one—even if the bare intentions are precisely *to* make sense of these experiences or to improve them. In either case, we are imposing our own sense of these experiences and, in so doing, are silencing an articulation of these experiences from an extraordinarily privileged standpoint: the position from which they are experienced. While it may seem like we have some *prima facie* good reasons for preferring an account from an outsider's perspective (such as in the case of the expert opinion of a physician) over a subjective account, upon closer scrutiny, we have demonstrated that these accounts are not to be automatically and unproblematically understood as superior to subjective accounts. Anita Ho writes,

> In attempting to acquire a fuller appreciation of the state of affairs, we need to acknowledge that the patients are the ones who are likely most knowledgeable about what their impairments and various clinical and nonclinical management strategies mean to them—they may be "experts" in that regard. Clinical expertise in assessing various conditions, while important in promoting medical care and sound policies, is only part of the story. It is only when we also incorporate patients' perspectives or assessment of

> their situations that we can ascertain appropriate care plans and practice guidelines. (119)

There are, thus, practical implications for our "getting it right," along with key epistemic implications. We must extend the applicability of Ho's claim beyond the realm of patients, however, as disability does not necessarily link up with disease and disabled individuals, therefore, are not all to be understood as patients.

The epistemic consequences of the sustained commission of hermeneutical injustice by dominant groups are extensive. Without a proper recognition of what the world is like to a socially marginalized other, members of the dominant group can suffer from a lack of curiosity (Medina, 33). As a product of there being aspects of reality that one need not explore (e.g. the experiences of marginalized others) because one is in the dominant group one may not develop any curiosity about what goes on in those overlooked territories. Such a lack of curiosity can lead to the vice of epistemic laziness; only the things that come easily to us are the things worth knowing (Medina, 33). Knowledge gleaned from the easiest method of our acquiring it is the only knowledge worth having. And finally, those in privileged epistemic positions can be epistemically arrogant (Medina, 32). The knowledge one has (the knowledge already limited by a lack of curiosity and epistemic laziness) is preferable and authoritative. To recap, the key epistemic consequence for the oppressed is severe epistemic insecurity: a misguided opinion of their epistemic agency suggesting their intellectual inferiority (Medina, 41).

From either standpoint, then, we have good reason to look for an effective method for dismantling instances of hermeneutical injustice and reducing or eliminating the epistemic vices it promotes for both parties. At this point, however,

we must return to the question of whether we have an individual obligation to do so. I have already argued that, as a member of an oppressed minority, one would not necessarily have such an obligation—although they may indeed have an interest or desire. I will now argue that individual members of the dominant group do have an obligation to rectify hermeneutical injustice when and where they encounter it.

Recall that, for Fricker, there are no individual responsible parties in the commission of hermeneutical injustice. Hermeneutical injustice is a product of the operation of the dominant discourse's understanding of a minority group's experience in such a way that their experience is not properly understood. We all, whether members of the dominant group or not (have to) make use of the dominant discourse's understanding of a phenomenon to make sense of our experiences. If the dominant discourse is all that we are operating with, however, and we are not receiving any input from minority groups, then we are not in a position to develop an appropriately robust sense of self which would then include information about what we are like from alternative perspectives. In the case of minority experiences, however, it can lead to hermeneutical injustice. But the dominant discourse is, in part, an epistemic byproduct of unjust systems of oppression operating in our society. There is, therefore, on Fricker's account, no one responsible party for a case of hermeneutical injustice. Even if we reduce it to the consideration of a single member of the dominant group misunderstanding, overlooking, or minimizing of the experience of a single member of an oppressed minority's experience—that one individual is not in any way culpable for their inability to understand the other's experience. Both parties are acted upon by the dominant discourse's ability or

inability to account for that experience. It is not that person's fault they do not understand. Fault and responsibility properly lie at the level of society on the whole.

Failure to claim individual responsibility for our epistemic location is unjustifiable. Yes, as members of the dominant group, we may have cultivated a set of epistemic vices that makes it the case that committing hermeneutical injustice is likely. And it may not (likely is not) our fault that we happen to be members of the dominant group. But by being a member of the dominant group, we are only more *likely* to develop these vices. We cannot make a universal claim that all members of the dominant group are epistemically arrogant. In that way, even though it is impossible not to be influenced by dominant discourse (no matter your social location), it is not the case that you bear no responsibility for epistemic arrogance if you have it. If we take Fricker's view—the absence of hermeneutical resources amongst the non-dominant group in the first place—then to hold someone accountable for their arrogance would be unreasonable, in that there is nothing for them to be excluding and, in so doing, bolstering their own interpretation of the circumstances and thus developing arrogance. In the same way moral virtues are cultivated—by keen self-awareness and habituation—so too are intellectual virtues. We are responsible for our own self-awareness and we are responsible for our own regimen of practicing virtuous acts until they become second nature. In that way, we are each individually responsible for hermeneutical injustice at the societal level. By taking individual responsibility and enacting change, we can, in the same way, begin to dismantle it. By disallowing individual culpability and responsibility we endorse an attitude of accepting the status quo. Societal change must still begin with the

individual, and with an understanding of society usurping responsibility, individual change is unlikely to manifest. Similar to the bystander effect in psychology, where individuals are not motivated to action because they assume, with so many others observing, surely someone else will intervene—in the case of hermeneutical injustice, we cannot allow the individual to assume it is the responsibility of another to take action simply because so many are involved. Doing so perpetuates inaction and, therefore, perpetuates injustice. For Medina, as long as we are involved, we are perpetrators (111). With this contention, I wholeheartedly agree.

As members of the dominant group, what, then, is our individual responsibility to undermine hermeneutical injustice? How can we best combat this phenomenon? The core problem of hermeneutical injustice is not being able to understand what it is like for an epistemically located other. Because hermeneutical injustice is the product of a system of general oppression, it is only through sustained, often uncomfortable, interpersonal contact with the epistemic other that we can overcome it. We must therefore leave the comfort of our epistemically privileged positions and enter into the worlds of oppressed others. We must enter their worlds in a particular way: one that invites the same vulnerability they experience when entering our world. This vulnerability is characterized by having one's identity at least in part defined by the ways in which you are viewed by others. If we are unable or unwilling to attend to differences, then we are not in a position to understand ourselves completely. In order to have more complete self-knowledge, we need to know something about ourselves relationally. Medina writes,

> In our communicative interactions we must make room for eccentric voices and we must respond to their nonstandard ways of entering into communicative dynamics. Being hermeneutically

> open means being alert and sensitive to eccentric voices and styles as well as to nonstandard meanings and interpretive perspectives. (114)

In a groundbreaking piece entitled, "Have we got a theory for you!," Maria Lugones and Elizabeth Spelman speak back and forth and in unison to begin to articulate what is wrong with (at the time, predominantly white) women's feminist theorizing for women of other oppressed minority identities. In this case Lugones attempts to articulate the problem of feminist theorizing for Hispanic women. While feminist theorizing was born out of the desire of women to be heard, to have their experiences understood in an androcentric society, in so doing, it made some initial missteps in lumping the experiences of women together. It is clearly not the case that in society at large the experiences of all are properly expressed or can be understood by way of generalization, yet this is a problem within minority communities as well. The problem seemed to be that white feminist theory had the same impact on women of other minority identities that androcentric theorizing had on women. We can see this problem becoming a stumbling block for our case of interest as well: how can we speak of those who socially identify as disabled as having a unified voice? While their general engagement with this identity allows us to speak of them as a group, it is impossible to make the claim that people who are disabled in different ways or to different degrees share the same experience—and even if their disabilities are the same, we cannot know for certain that they have ascribed the same social meaning to them.

This problem of generalization does not have to be a defeating one, as we learn from the dialogue of Spelman and Lugones. In articulating the problem, Lugones describes for us a classic case of hermeneutical injustice: "We try to use

[your language] to communicate our world of experience. But since your language and your theories are inadequate in expressing our experiences, we only succeed in communicating our experience of exclusion" (575). Here Lugones is literally worried not just about the negative valence associated with the term 'lesbian,' but, more simply, about the literal translation from English to Spanish: where 'lesbian' translates to 'perversion.' Which is why she finds herself at a terrible loss for words in this case, yet the problem she expresses is a general one. When we come to you, when we do things your way, our experiences are inexpressible and therefore lost. All we can do from this position is point to that fact. Yet Lugones warns that "we either use your language and distort our experience not just in the speaking about it, but in the living of it, or that we remain silent. Complaining about exclusion is a way of remaining silent" (575). This expresses something of a hopeless standstill. The way feminist theorizing was being done was actually having the effect of silencing the voices of some women. In an effort to combat hermeneutical injustice for one group, feminist theory was in effect causing it for another.

Lugones goes on to describe how different it is for a member of a minority group to be in the dominant group's world from a member of the dominant group being in the minority group's world. In both cases, she describes these individuals being ill at ease. We have seen the way in which the individual member of a minority group may be ill at ease in the dominant group's world. Their experiences are misunderstood, indescribable, invisible. In section one, some of the potential epistemic benefits for a member of a minority group operating in the dominant group's world that fall out of these consequences were discussed. Yet minority group

members have no choice but to function in the world of the majority. They must do so in order to achieve gainful employment, acquire an education, etc.. Lugones writes,

> [w]hen we are in your world many times you remake us in your own image, although sometimes you clearly and explicitly acknowledge that we are not wholly there in our being with you. When we are in your world we ourselves feel the discomfort of having our own being Hispanas disfigured or not understood. (576)

An individual member of the dominant group has a choice of whether or not to enter the world of a minority group. If they do so, Lugones argues, they, too, will be ill at ease, but in a very different way. She writes,

> there is nothing that necessitates that you understand our world: understand, that is, not as an observer understands things, but as a participant, as someone who has a stake in them understands them. So your being ill at ease in our world lacks the features of our being ill at ease in yours precisely because you can leave and you can always tell yourselves that you will be soon out of there and because the wholeness of yourselves is never touched by us, we have no tendency to remake you in our image. (576)

This discrepancy in what it means and feels like to be ill at ease in the worlds of others is highly problematic. Individuals of minority groups participating in the dominant group's world is, in the first place, not optional. In the second, it is formative of their identity. In the case of a member of the dominant group entering the world of a minority, this entering is (1) optional, and (2) in no way necessarily formative of their identity. There is no corresponding take-away from this direction of travel. Without it, there can be no genuine understanding of the experiences of another. Part of the minority experience is having your self-identity informed by the views of others. In coming to understand the experience of another, our self-identity has to be informed a necessary recognition of the way they view us. This is part of the "what it is like."

Lugones proposes a solution to counteract the unbalanced way in which someone in a position of power enters in to the world of a minority other. This solution has everything to do with our motive for action. She writes,

> The only motive that makes sense to me for your joining us in this investigation is the motive of friendship, out of friendship. A non-imperialist feminism requires that you make a real space for our articulating, interpreting, theorizing and reflecting about the connections among them-a real space must be a non-coerced space-and/or that you follow us into our world out of friendship. I see the 'out of friendship' as the only sensical motivation for this following because the task at hand for you is one of extraordinary difficulty. It requires that you be willing to devote a great part of your life to it and that you be willing to suffer alienation and self-disruption. (576).

So, in effect, because of the significant potential negative impact to this individual, her motivation for entering the minority group's world in a way that similarly exposes her to the threats experienced by minorities entering the dominant world, and therefore rendering intelligible their experiences, has to be a untainted one.

Going as a missionary, to enforce your system of beliefs won't do. Going as an anthropologist, to serve your self-interest of data-collection won't do, either. The motivation for going has to, in some way, equalize the differences between these individuals or the effect will not be a genuine understanding of what it is like. The model of the relationship of friends serves as a perfectly suitable one for equalizing these differences. Genuine friendship is a relationship among equals. Traveling to another's world in the service of becoming their friend puts you on more equal footing. Having this equal footing exposes you to this same suffering of "alienation and self-disruption" that a member of the minority group experiences when she travels to the dominant group's world.

In their joint discussion concerning what makes a theory a helpful one, Lugones and Spellman articulate one feature of such a theory that I believe is a helpful guidepost as we consider how to go about doing what we're talking about: trying to properly grasp the experiences of socially located others. They argue that a theory is helpful if it:

> enables one to see how parts of one's life fit together, for example, to see connections among parts of one's life one hasn't seen before. No account can do this if it doesn't get the parts right to begin with, and this cannot happen if the concepts used to describe a life are utterly foreign. (578)

We need to keep these metrics in mind as we go on to articulate the best way in which to foster hermeneutical justice. Losing sight of our objectives, which are highly consistent with the claim made here about useful theorizing, may make it the case that our recommendations are not sufficient for getting the job done.

In elucidating the way in which those in positions of power need to enter into the worlds of the oppressed, Lugones specifically spells out some of the conditions for being in their world in the same way in which they are in yours:

> So you need to learn to become unintrusive, unimportant, patient to the point of tears, while at the same time open to learning any possible lessons. You will also have to come to terms with the sense of alienation, of not belonging, of having your world thoroughly disrupted, having it criticized and scrutinized from the point of view of those who have been harmed by it, having important concepts central to it dismissed, being viewed with mistrust, being seen as of no consequence except as an object of mistrust. (580)

Satisfying these conditions makes it the case that your experience of coming to their world will not be an imperialistic one. These are features of what it is like to be in the dominant world as a member of an oppressed group. Without these same features in play, you will not sufficiently know what it is like for them when they come to you

and, if you do know that, you miss out on something that is central to their experience.

Lugones explores some possible motivations for someone going to such extreme lengths in this process. First, she wants to rebut the possibility that someone would do this out of self-interest. She considers motives of self-interest such as spying, and coming to a fuller understanding of oneself. The latter of these self-interested motives is relevant to our discussion. Lugones believes that one would not do this because it is unreasonable to have the expectation to come out of such an experience "whole" due to the destabilizing effects of experiencing oppression. I argue that one does gain self-knowledge by engaging in such a practice, but not that one comes out of it "whole" or unchanged. In fact, coming out of the experienced with a fractured sense of self is indicative of having done the job right. This is what it feels like for them. This is what it should feel like for you.

She also rejects the potential for obligation to be a motive, comparing it to making love to someone out of obligation (581). In this way, I think Lugones gets something wrong. Her analogy suggests that this action is simply to discharge some duty one has to another by engaging in an intimate act without a corresponding reciprocal intimate need being satisfied. Harm has been done to the oppressed group. Engaging in this behavior is a way of rectifying that harm, of filling in these hermeneutical gaps. The oppressed group is not being used as a mere means for the epistemic other, although they are being used as a means. What makes this fact justifiable is that each party is using the other as a means to an end. On the one hand, to hear, and on the other, to be heard. Both have an interest in this exchange. In this

way, both parties are intimately engaged and the analogy of making love out of obligation seems inappropriate. I want to maintain that this act can and should be performed out of obligation, but doing so does not render the oppressed party a mere means, nor does it suggest that the intimacy of the act is nonreciprocal.

Yet all this work of rejecting possible motives is only building to a stronger case for accepting the motive she previously posited as the appropriate one behind this exchange—the motive of friendship. And with that contention, as I have previously indicated, I have no issue. By pushing beyond obligatory motivation we are left with friendship. I believe that the model of the relationship of friendship is a helpful, important, and quite possibly necessary one for the work we have in mind. Lugones writes,

> If you enter the task out of friendship with us, then you will be moved to attain the appropriate reciprocity of care for your and our wellbeing as whole beings, you will have a stake in us and in our world, you will be moved to satisfy the need for reciprocity of understanding that will enable you to follow us in our experiences as we are able to follow you in yours. (581)

The process outlined by Lugones and Spelman becomes the thrust behind Lugones's later work, "Playfulness, "World"-Traveling, and Loving Perception." In it, Lugones continues to warn against arrogant perception and argues instead for "loving perception" (420). Her notion of loving perception is deeply rooted in identifying with the subject of your perception. She writes, "there is a complex failure of love in the failure to identify with another woman, the failure to see oneself in other women who are quite different from oneself" (422). Additionally, Lugones argues that a similar failure occurs when you do not adequately recognize as a part of yourself the ways in which others perceive you (424). We have already documented

this as an essential element of *knowing what it is like*. In identifying someone as the "other," we are saying something about her, something about her in relation to ourselves, and something that she has to internalize to operate in the world, but also, we are saying something about ourselves—a point that often gets missed. . If we are to properly know what it is like, then we need to incorporate as essential the conclusions others draw about us and about us in relation to them. Lugones writes, "The reason I think traveling to someone's "world" is a way of identifying with them is because traveling to their "world" we can understand *what it is to be them and what it is to be ourselves in their eyes*" (432).

Finally, Lugones identifies four ways in which we can be at ease in a world (427). The first is being a "fluent speaker." What she means by this is that one knows all of the right words to be used and the right ways of acting (not quite our ordinary sense of the term). The second is by being "normatively happy," or by being in agreement with the customs. The third is by being "humanly bonded" by loving others or others loving you. The final way in which one can be at ease in a world is by having some shared history in common.

In carrying out this practice of world-traveling then, we have a lot to keep in mind. First, we have to come to these other worlds primarily in the service of friendship. Second, we need to accurately see the multiplicity of views of ourselves represented to us in that world so we can work to fit them together as essential elements of our own self-identity. Third, we need to come humbled and free from imperialistic attitudes and intentions. Fourth, we need to identify with the other. And finally, we need to find a way to become at ease in that world. If all of these

conditions can be met, then it is my contention that through the application of Lugones' wore we can begin to adequately claim *to know what it is like*.

Our final concern to address is whether or not world-traveling is an adequate framework for *knowing what it is like* to be disabled. To respond to this, we must consider whether each of the five essential features of world-traveling is possible in this case of an able-bodied individual attempting to bridge a hermeneutical gap between the dominant discourse's understanding of the experience of disability and the experience of disability to someone who is, in fact, disabled. If we are able to satisfy each of these five conditions in our case at hand, then we are positioned to conclude that world-traveling is indeed a useful way of rectifying the hermeneutical injustice done to this community. Let us, then, take each consideration in turn.

First, we have to ask ourselves whether the motive of friendship is a plausible one behind an able-bodied individual's movement into the world of someone with a disability. I think the answer to this question is an obvious one. Surely the differences between able-bodied people and people with disabilities does not automatically preclude the possibility of genuine friendship. Even if there are alternative motivations operating in the background, such as performing an act of charity, or wanting to understand someone better, genuine friendships can and do flourish between able-bodied and disabled individuals all the time. An example of this might be a high school or college student satisfying a service-learning requirement for the completion of their degree. Suppose the student chooses to work with a program matching volunteers to individuals in the community with Down syndrome with the aim of enriching both of their lives and fostering compassion and awareness about

Down syndrome among young people. While the initial pairing of these two individuals may have been obligatory and random, there is no reason to suppose that a genuine relationship of friendship couldn't flourish between them. They may find that they share interests such as playing basketball or collecting coins and spend their time together engaged in such activities while learning more about one another at the same time. These friendships can be mutually fulfilling and provide the requisite "equal-footing" for understanding the world in which a disabled person lives.

Second, an able-bodied person must be able to get an accurate picture of the multiple views persons in a disabled community may have of them, and go on to piece these together as an essential part of their own self-understanding. I think in cases where a disabled person is able to communicate effectively their opinions of this individual to them and feels safe and comfortable in doing so, there is no reason to suppose why the project of piecing together a sense of self from these differing perspectives must be a barrier. Suppose a hearing person learns American Sign Language and pursues a career as a translator. In this line of work, it is likely that she would encounter innumerable deaf individuals and may even encounter them in highly intimate places, such as if someone were an interpreter working at a hospital. Through her interaction with each person with whom she works, she would likely be privy to a diverse array of attitudes expressed toward her and her presence in the situation, and, additionally, a glimpse into attitudes about interacting with the hearing community in general.

In some cases, she may be made to feel intrusive or unwanted, in others she may get a sense of gratitude, and still in others she may pick up on frustrations or

difficulty a deaf person is facing in attempting to communicate with someone who is not sensitive or responsive, or acting uncomfortably or awkwardly in the presence of someone who is deaf. In any of these scenarios, the interpreter is likely able to get some sense of that individual's feelings about her, her role, and even that person's attitude towards someone else—someone else who represents another member of the dominant group. These feelings and attitudes may be being conveyed by the deaf person to the interpreter unwittingly or through their direct interaction. Through these experiences, the interpreter is able to piece together a more complete picture of herself by including in her own self-conception the feedback she gets from the various deaf people that she works with or develops friendships with.

The third condition to be met for world traveling is to come to someone else's world humbly and without imperialistic attitudes. Again, I see no necessary barrier to this occurring. Of course, it is always going to be the case that an able-bodied person initially enters the world of someone with a disability with the dominant discourse's conception of what it is like to have a disability operating in some way, whether in the foreground or the background of this person's mind. The question is really one of whether these preconceptions can be "left at the door," or shed along the way. Many of the operational conceptions of people with disabilities in the dominant discourse are overwhelmingly influential, in particular, I think, the sentimental and biomedical narratives of disability. But I believe that the appropriately dispositioned person, although they might struggle with it, would eventually be able to approach someone with a disability with the humility to admit that their conceptions of living with a

disability are informed by something other than accounts of the subjective experiences of people who are actually disabled.

For the most part, I think a person with a disability would expect these preconceptions to be in operation and may even be slightly disarmed by someone who would freely admit such a thing. Ideally, this would encourage the person with the disability to begin to tell the subjective side of the story and, when an able-bodied person is exposed to this, they can begin to make room for the subjective account in their understanding of living with disability, and they can begin to do it by examining their preconceptions in light of this new information and rejecting any former conceptions that do not fit. This would exhibit the epistemic virtue of open-mindedness which, although it is more easily achieved by individuals in oppressed groups, can be cultivated in individuals belonging to the dominant group as well.

The fourth condition to be met for world traveling would constitute the able-bodied person's ability to identify with persons with disabilities. There is nothing to suggest that identification with a person with a disability is in any way more difficult than attempting to identify with an individual with any other minority identity. How do we identify with people who are unlike us? The answer, I think, is in isolating characteristics, circumstances, interests, and experiences which *are* like ours. Why should we think that there is any shortage of similarities between members of the dominant group and *this* particular minority group than any other?

Finally, although it is not entirely clear that this is a necessary condition, for successful world-traveling to take place, an able-bodied person has to somehow find themselves at ease in the world into which they have traveled. Recall, there are four

ways in which one might find oneself at ease. First, in becoming fluent in that world: an example of this may be a hearing person literally becoming fluent in American Sign Language, and then going on to immerse themselves in the deaf community to the degree that they become aware of any unique customs.

Second, in being normatively happy in that world: it is difficult for me to imagine what might be normatively different in a disabled community as compared to the dominant group, but I suppose I can hypothesize a few possibilities. One might be allowing mentally disabled individuals the ability to consent to having sex. Someone may or may not agree with this practice for various reasons yet, if they do agree, then they are to some extent normatively happy in that world. Another might be allowing Deaf parents to select for embryos that would develop into Deaf babies. Again, there are various reasons one might agree or disagree with this practice, but it is the case that hearing physicians have assisted Deaf parents in purposely producing Deaf children which suggests that it is at least possible for them to be normatively happy in that world.

Third, in being humanly bonded: this would be the case if love were possible between an non-disabled person and a person with a disability. Examples of this abound. Able-bodied and disabled people fall in romantic love all of the time. Able-bodied family members love and care for their disabled family members (although it might be argued that, by virtue of being related to someone with a disability, then they are already in that world) whether the disability was the result of an accident later in life or whether they may have been born with it. Finally, as we established at the outset of this investigation of applicability, genuine bonds of friendship can be

formed between able-bodied and disabled individuals and many friendships are characterized by love.

Fourth, in having a shared history: because in contemporary western society, for the most part, people with disabilities are fairly integrated into the community, able-bodied individuals and disabled individuals can have a shared history with respect to their shared participation in society. For example, an able-bodied person and a disabled person may work together. They would have a shared history with respect to what has occurred at their workplace over the course of time that they have been employed there.

In sum, then, all five conditions for successful world-traveling can be met for able-bodied individuals entering disabled communities. For this reason, it is possible that world-traveling is a viable avenue for *knowing what it is like* to be disabled. Because it is possible for an able-bodied person to know what it is like to be disabled, it is possible to bridge hermeneutical gaps between disabled communities and the dominant discourse. To do so would dramatically enrich our understanding of disability and rectify the hermeneutical injustice suffered by the disabled community at the hands of the dominant group. World-traveling, then, is a way in which one can cultivate the virtue of hermeneutical justice and increase our repertoire of epistemic goods. *Knowing what it is like*, as the distinct end-product of world traveling is something distinct from knowing a list of propositional facts about an experience. *Knowing what it is like* is an epistemic good that is at least on par with, and in the cases we have explored in this chapter, in many ways preferable to, mere knowledge acquisition. In fact, I believe there is reason to suggest that the practice of attempting

to learn as much as we can about epistemically located others can get in the way of *knowing what it is like*. Because *knowing what it is like* requires entering relationships with epistemic others with a great deal of humility and the behavior of fact-gathering seems to presuppose some superiority. On the one hand we are learning from and on the other we are learning about.

Conclusion

It has been argued that there are instances where the pursuit of knowledge inhibits our epistemic well-being. In these instances we are better off epistemically to resist the urge to pursue (certain sorts of) knowledge, recognize our ignorance and, in so doing, enhance our epistemic well-being. The cases explored have ties to biomedical or scientific ways of knowing: pregnancy, nursing, and disability. Yet it is argued that coming to know in this way can be harmful to us epistemically by achieving knowledge unsustainably, surrendering to epistemic imperialism, or committing testimonial or hermeneutical injustice.

While this type of information seeking raises unique issues, such as setting out the questions that are worthy of answering and the appropriate ways in which to go about answering those questions, it is my contention that these findings pertain to areas outside of medical technologies. One place we can begin to look is an example from literature.

In an alternative reading of Shakespeare's *Othello*, Naomi Scheman gives an account of what she takes to be the *real* harm committed by Iago (370). Her interpretation suggests that it is not that Iago convinces Othello that Desdemona has been unfaithful but instead that Iago changes the terms, or the nature of the evidence, required to establish feelings of mutual trust in their relationship. She writes:

> Iago's skillful manipulation of the appearances (he doesn't exactly *lie*) is not a perversion of scientific reasoning, but, in its power to seduce Othello, a demonstration both of the incapacity of such reason to comprehend aspects of the world that lie beyond it and the defenseless inability of that world to provide a logical, rational proof of its own reality. It needs – demands – no proof, but pressed to give one, it will inevitable fail. (370)

This can be seen as a move similar to the one being made by medical professionals in the case of the relationship between mother and unborn child. What was once a

relationship built on merely the emotional and intellectual insights of the mother (and the other women surrounding and attending to her during the pregnancy and labor) and the physical sensations of the mother alone is now a relationship forced to fit into an unfamiliar mold, subjected to novel questions as well as procedures for answering those questions which are responsible for changing the character of their relationship.

We ought to ask ourselves who Iago is to set out the questions at issue in the relationship between Othello and Desdemona. We ought to ask ourselves who the doctor is to set out the questions at issue in the relationship between mother and child. It is time, then, to establish *our own* questions, to determine for *ourselves* reliable methods of answering them, and to provide some tentative answers. The question proposed here, again, is whether knowledge is always more valuable than ignorance. The reasoning behind the response I advocate involves a recognition of some potential 'epistemic harms.' Epistemic harms can be understood very much like physical harms: they are the intellectual harms suffered by the knower and the known alike resulting from certain types of knowledge gaining procedures and, in some cases, from the mere knowledge gained by itself. We have encountered several of these already, including the impact of ultrasound use on the perceptions of the mother regarding her baby and the thrust of probabilistic knowledge of risk to pursue more and more evidence to engender worry and fear.

Iago here functions precisely like the physician in the pursuit for information in pregnancy. Iago sets the standard of proof in the same way that technologies available to pregnant women set the standard of proof for information about their unborn child. By raising the standard of proof, Iago shifts the ability to provide that

proof away from Desdemona in the same way that medical technology shifts the ability to provide that proof away from the mother. The degree of certainty required to count as knowledge is artificially heightened.

In the formulation of our most basic relationships we agree to a certain amount of blind trust. This trust ought not to be understood as wrongheaded. Trust is what allows us to build relationships with others, to learn from others. What this trust does not do, however, is submit to logical proof. When pressed to conform to these heightened standards, trust built in loving relationships cannot provide. Iago's deception convinces Othello that his relationship to Desdemona must submit to these high standards of proof. Iago convinces Othello that trust isn't enough, that trust does not equate to knowledge, that trust does not establish proof. It is in consideration of the function of trust and knowledge in loving relationships that I believe is the most promising area for the future application of the present findings. Trust bolsters testimonial credibility.

Iago's temptation takes many forms in contemporary culture. The ease with which we have access to information regarding another is unprecedented. Pursuing this information is as simple as typing a name into a search engine. Suppose you were interested in learning more about a new friend or a potential date. By "googling" that person, you have unprecedented access to all kinds of information about them. You might learn where they work, where they went to school, whether they have children, their relationship history, anything they happen to share about themselves on social media, and even whether they have any court proceedings on the public record. You might develop a distaste for that individual prior to even meeting them. By pursuing

that information ahead of time, you work to head off any future ability they have of characterizing that information in their own way.

If we unearthed any information about that person's relationship history, we could begin to develop a picture of that person that is in no way reflective of the meaning they have ascribed to their own history. In this way, we commit hermeneutical injustice by preventing their own depiction of their past to gain credibility with us as worthwhile information. Instead, we build our own understanding without any attention to the way in which it is seen through another lens—through the lens of the very person we are attempting to make sense of. Undeniably, individuals are in a privileged place to make sense of their histories for others, to contribute to and shape depictions of themselves for the others that they meet. This seems like one of the most basic ingredients of establishing relationships with others. It is not what other people say about that person that should count for us, it is what he or she says about him or herself.

We need to allow space for relationships to develop without the pressure of logical proof and the weight of outside information dictating how we see and what we believe about others. Coming to know another person adequately requires that we begin to see them, and even begin to see ourselves from their angle. The dictates of world traveling necessitate that we take seriously the interpretations of epistemic others when we attempt to make sense of a situation or a relationship. Without giving adequate consideration to the way in which another sees us or sees themselves we violate the stipulations of world traveling and we subject others to our own epistemic imperialism.

While these avenues promise fruitful application, I believe that the most appropriate venue remains within the field of biomedical research. As technologies advance, it can be predicted that the kinds of things we set out to know will also advance. With the capabilities for different sorts of investigation growing, the information we seek will continue to shift. If we are not careful in working out for ourselves what it is we want to know and the ways in which we feel comfortable seeking out information, we risk losing sight of our own interests and becoming mere objects of investigation. Medical technologies have worked to shift the location from which questions are being asked. It is no longer the patient's role to ask questions, to limit inquiry into their own care. That power and control has come to the physician instead. As patients, we must be careful to exert limitations on the number and nature of investigation into ourselves. Projects like unraveling the human genome and origins research in pregnancy, while exciting, make available information that we're simply not ready to behold, information we may not want others to have access to either.

It is my hope that after reading this work we find ourselves better poised to answer the question of whether or not we should pursue knowledge of x. Our epistemic projects must not be shaped by the Iagos of this world, but instead by our own interests and desires, and a concern for the avoidance of the commission of epistemic harm.

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